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**THE SIGNIFICANCE OF MEANING-MAKING, AGENCY AND SOCIAL  
SUPPORT: A NARRATIVE STUDY OF HOW POOR WOMEN COPE WITH  
PERINATAL LOSS**

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### **Declaration**

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work or works of other people has been attributed and has been cited and referenced.

**Signature.....**

**Date.....**

University of Cape Town

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The participants, who told their painful stories to me with dignity and courage.

University of Cape Town

### **Dedication**

This study is dedicated to our son, Ian, born 25 April 1990, died 28 April 1990.

### **Abstract**

Perinatal loss (stillbirth or the death of a neonate) can result in considerable psycho-social disruption for mothers. As women grieve, they try to make meaning of the death of their baby. In contexts of social and economic deprivation, perinatal loss often occurs alongside other difficulties which may affect and limit women's ability to make meaning. A narrative approach was used to explore how meaning-making functions in such contexts. In-depth interviews were conducted with 15 women who had experienced perinatal loss while attending a state maternity hospital. Narratives which the mothers constructed of the event were examined in order to understand what meanings they derived from the loss, and how these were (or not) achieved. These narratives were often linked to other stories of pervasive life difficulties. Despite their difficult contexts, the bereaved mothers engaged in meaning-making in similar ways to those described in previous studies in more affluent settings: they attempted to integrate the loss with their identity and goals, they affirmed the baby as a real person to be mourned and they searched for reasons for the loss. The effect of their contexts on meaning-making was mediated by social support and personal agency. Where one or both of these were present, the bereaved mothers were able to find meaning in their loss; women who had neither seemed unable to do so. Those who portrayed themselves as agentic were able to reflect on their experience and make decisions to change their lives. Mothers with strong social support made meaning through conversations, social validation of the loss and social help which mitigated against the sense of helplessness engendered by their loss and circumstances. It is recommended that hospital and counselling services implement practices which help to build or consolidate personal agency and social support to facilitate successful meaning-making following perinatal loss.

**Keywords:** perinatal loss, grief, poverty, context, narrative, meaning-making, agency, social support.

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## Chapter One: Introduction

Perinatal loss through stillbirth (*in-utero* death of a foetus over 500g/24 weeks gestation), or early neonatal death (within eight days of delivery) can have a profound psychological and psychosocial impact on parents. Many studies consistently attest to the intensity of grief reactions, which are sometimes greater than when a spouse or a parent dies (Neria & Litz, 2004; Wing, Burge-Callaway, Rose-Clance, & Armistead, 2001). Bereaved parents, especially mothers, can be at risk of mental health complications such as Post Traumatic Stress Disorder (PTSD), depression, anxiety, and chronic or complicated grief (Hughes, Turton, Hopper, & Evans, 2002). Approximately one in five mothers struggles with enduring adjustment problems (Bennet, Litz, Maguen, & Ehrenreich, 2008; Froen et al., 2011).

### Perinatal Loss in the Developing World

Although perinatal loss affects women of all demographic groups, countries of the developing world carry the greatest burden of pregnancy loss. Stillbirths are consistently under-reported in developing countries, but estimates put them at 26/1000 live births, more than four times higher than western figures (de Kok, Hussein, & Jeffrey, 2010). Of the 3 million stillbirths and 4 million annual neonatal deaths, 98% and 99% respectively occur in low and middle income countries. Most of these could be avoided: only half of births are attended by a skilled assistant (Mullan & Horton, 2011). In South Africa, the perinatal mortality rate is 38/1000 live births (Saving Babies 2008-2009, 2010).

Advances in medical technology in developed nations have led to a gradual decline in perinatal mortality figures. This may have led to an expectation that loss will very seldom, if ever, occur, which makes it even more shocking when it does (Robinson, Baker, & Nackerud, 1999). Within the developing world, the fact that many babies die unnamed and unrecorded is indicative of the perceived inevitability of their deaths (Lawn, Cousens, & Zupan, 2005). A recent South African survey shows that the infant and under-five mortality rate was twice as high in the poorest as in the richest quintile (Gilson & McIntyre, 2007). Poverty is frequently an underlying cause of perinatal loss, either through reducing access to effective care, or heightening the prevalence of risk factors, such as poor maternal health, and the necessity of continuing with hard manual labour far into a pregnancy (de Kok et al., 2010; Haws et al., 2010). Lawn et al. (2005) refer to the “three delay” model which affects the delivery of health care in poor communities: delay in recognition of illness, delay in seeking and accessing care and delay in provision of care at the health facility. Gilson and McIntyre (2007) found that although poor people experience more ill-health than those in higher income groups, they

generally are less adept at recognising illness and injury, and thus less likely to seek help. Kavanaugh and Hershberger (2005) found a similar misreading of symptoms by bereaved mothers in their study of low-income African American parents.

Late antenatal care attendance has been identified as one of the avoidable factors underlying perinatal mortality (Saving Babies 2008 - 2009, 2010). Women book late for various reasons, many of which are related to their socio-economic position. These include difficulty in getting time off work, low education level, lack of social support, difficulty in accessing health care services, and dissatisfaction with these services. Personal reasons for late attendance are having an unstable relationship with the baby's father and an unwanted pregnancy. Many women experience the nurses as neglectful and abusive which discourages them from attending the clinics (Abrahams, Jewkes, & Mvo, 2001).

As a result of inadequate communication efforts by the medical establishment and/or the power differentials which render the poorest and least educated as unworthy of much attention, parents are often unable to access medical explanations as to why their baby died. According to de Kok et al. (2010), "...being a women, and being poor, increases the risk of experiencing loss, aggravates its consequences, and limits one's options to prevent, manage, and cope with loss" (p.10).

### **Research on Grief Following Perinatal Loss**

While a great deal of research on the parental grief following perinatal loss has been conducted in the West, predominantly among a middle-class population, it has received very little attention in developing countries. Medical anthropological studies in low and middle income countries have focussed on social aspects of pregnancy loss, but not much is known about how mothers grieve (van der Sijpt & Notermans, 2010). Research in the West has been dominated by traditional grief theories, which assume that the bereaved need to "work through" their grief, in order to reach a resolution. Grieving is expected to follow a particular pattern and expression - any deviation from this is considered pathological (Krueger, 2006; Neimeyer, 2000). Although many of the studies pay attention to immediate context, none gives serious consideration to the effects of the broader context.

A new wave of grief theory, based on social constructivist approaches, highlights the role of meaning-making in grieving. Janoff-Bulman's (1992) assumptive world theory posits that traumatic loss (such as the death of a baby) shatters fundamental beliefs about the world and disrupts the ability to make sense of life. The grieving process of parents following perinatal loss can be seen as an attempt to reconstruct meaning and integrate the death of the baby into their lives in a meaningful way. Meaning reconstruction is undertaken on personal

and social levels (Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010; Uren & Wastell, 2002; Willick, 2006). This framework opens the possibility of exploring how the interaction between contextual and personal factors influences the grieving process.

### **Aim of this Study**

This study builds on research conducted as part of a Psychology honours thesis in 2010 investigating meaning-making following neonatal death among Xhosa-speaking women. Although the meaning-making paradigm helped to elicit some valuable insights, the findings of the study suggested the need for further investigation into patterns of meaning-making among women whose socio-economic circumstances result in ongoing concerns about material security and/or daily survival, render them vulnerable to multiple losses or trauma, and exclude them from access to private health care. This study therefore aims to examine how mothers whose “options to prevent, manage, and cope with loss” (de Kok et al., 2010, p.10) are limited by their socio-economic contexts make meaning following perinatal loss.

### **Structure of this Dissertation**

Chapter Two provides an overview of relevant literature. It discusses studies conducted in the West, as well as in the developing world, and attempts to make links between them. Grief theories are examined briefly, with a particular focus on meaning-making. The relevance of these to perinatal loss is suggested.

Chapter Three presents the methods used in this study. It begins with describing the study setting and outlining the research aims. The study design is then explained, followed by an outline of sampling method, a description of the participants, explanation of data collection and analysis, and finally, an examination of ethical and validity issues.

Chapter Four presents the results which emerged from analysis of the data. This is divided into three sections: the first section outlines how the participants described and experienced their contexts; the second describes common meaning-making patterns; and the third explores how sense of agency and social support affect meaning-making.

The final chapter summarises the main findings and discusses the limitations and significance of this study.

## Chapter Two: Literature Review

Research into the effects of perinatal loss has developed in two distinct streams. Before the 1970s, parental grief was largely ignored in the West. The baby's death was minimised by the rapid removal of the body, and parents were encouraged to get on with their lives and fall pregnant as soon as possible. A seminal study by Kennell, Slyter and Klaus in 1970 (cited in Badenhorst & Hughes, 2007) drew attention to the extreme distress which many mothers experienced as a result of neonatal death. This gave rise to a steady stream of research, primarily out of a concern to establish an effective way for medical staff to respond to parents' short term needs (Badenhorst & Hughes, 2007; Zeanah & Harmon, 1995). Research focussed on grief symptoms and mental health problems over various periods of time after the loss, and later expanded to investigate factors which hindered or facilitated healthy grieving. Most of these studies used traditional quantitative research methods. More recently, as interest in the phenomenology of perinatal loss has evolved, qualitative studies have explored women's interpretations of their experience. In the majority of these studies, participants were drawn from a white, middle class population. The focus was on individuals' grief, with little attention being given to social context (Bennet et al., 2008; Willick, 2006).

With so many other social problems to deal with, care for parents who lose babies has not been seen as a priority in low-income countries. In Africa specifically, reproductive research before the 1990s centred on concern for overpopulation, infertility, and induced abortions. More recently, medical anthropology, medical sociology and feminist studies have attempted to give voice to marginalised groups, focussing on social ramifications of pregnancy loss (van der Sijpt & Notermans, 2010). Few of these studies (apart from Modiba and Nolte (2007) in Gauteng and Obi, Onah, and Okafar (2009) in Nigeria) specifically examine mother's grief from an individual mental health perspective.

These two very different research paradigms promise a rich understanding of perinatal loss, as the findings from each are repeated, complemented and challenged in the other. In this chapter, different perspectives from research conducted in the West and in developing countries are drawn together in order to address the question of how perinatal loss affects mothers. The first section will focus on the psychological and social difficulties following the loss. The second section discusses factors which either protect against or increase vulnerability to prolonged adjustment difficulties. The third section explores the effect of personal and social meanings of pregnancy on grief. The final section addresses the relevance of grief models to perinatal loss, with particular reference to the meaning-making model.

## Effects of Perinatal Loss

Perinatal loss can cause deep emotional distress, family difficulties, and social disruption. These will be outlined in some detail, followed by a discussion of Prolonged Grief Disorder (PGD) which may be a long-term psychological sequel to the loss if coping skills and social support fail to facilitate adjustment to bereavement.

**Emotional distress.** Although there is great variation in the way women react to perinatal loss, common grief responses have been well documented. These include a wide range of emotions: anger, shock, denial, sadness, numbness, guilt, confusion and loneliness (Brownlee & Oiken, 2004; Wing et al., 2001). Grief can be unexpectedly pervasive and enduring. Although intensity of grief subsides after the first year, many parents still feel sad, guilty and angry after one to two years. Preoccupation with thoughts of the baby who died can continue for even longer, possibly indefinitely (Covington & Theut, 1993; Elklit & Gudmundsdottir, 2006; Lin & Lasker, 1996; Obi et al., 2009). Many women suffer from long-term depression and anxiety after the loss (Badenhorst & Hughes, 2007; Cacciotore, Schnebly, & Froen, 2009; Wing et al., 2001).

Mothers experience the loss as intensely personal, as if they have lost part of themselves (Cacciotore & Bushfield, 2007; Covington & Theut, 1993). Pregnancy and birth, even without trauma, evoke complex changes in a woman's sense of identity (Cacciotore, 2010). When a woman experiences a rapid return to a non-pregnant state with no dependent baby to nurture, she can deem herself to be flawed, incomplete, inadequate, and she may feel that her body has betrayed her (Bennet et al., 2008; McCoyd, 2010).

Some mothers display an absence of grief affect, which has been interpreted in different ways. Some researchers regard this as defensive, and others as well- adapted (Covington & Theut, 1993; Zeanah & Harmon, 1995). Reflecting on the wide range of grief responses evident in research findings, Bennet, Litz, Lee and Maguen (2005) conclude that, "essentially there is no normative or prescriptive mode of grieving: intense emotional expressions can lead to worse outcomes and apparent stoic reaction can lead to adaptive recovery" (p. 183).

**Self-blame and shame.** In attempts to reduce distress, many parents seek to find reasons for the loss, and often resort to blaming themselves or others (Covington & Theut, 1993; Modiba & Nolte, 2007; Wing et al., 2001). There is some indication that having a medical explanation for the death reduces distress, but this is not a consistent finding (Shreffler, Greil, & McQuillan, 2011; Wing et al., 2001). Conversely, lack of information

increases self-blame, and exacerbates anxiety in subsequent pregnancies (Shreffler et al., 2011; Theut et al., 1989).

Many mothers feel guilt over the death of their baby (Cacciotore, 2010; Covington & Theut, 1993; Kavanaugh & Hershberger, 2005). There are occasions when self-blame is realistic, based on factors such as not following medical procedures, but usually it is not and can increase feelings of depression and anxiety (Wing et al., 2001). Self-blame may be used by women who are in powerless situations to instil some sense of control by persuading themselves that their actions could have changed the outcome (Downey, Silver, & Wortmann, 1990). However, this has not been comprehensively investigated in the context of perinatal loss.

It is not always possible to separate the psychological from the social effects of perinatal loss in cultures which are collective rather than individualistic. For example, blame is construed somewhat differently in the studies from the low-income countries, where social friction is thought to cause pregnancy loss and “reproductive success is considered as dependent on relational harmony rather than mere individual health and biomedical parameters” (van der Sijpt & Notermans, 2010, p.392). Mothers are often accused by partners, in-laws or neighbours of deliberately jeopardising the pregnancy, or invoking bad luck through misdeeds and/or breaking customary tradition (Froen et al., 2011; Haws et al., 2010; Scheper-Hughes, 1985). The stigma of childlessness puts women at risk of shame and isolation. In order to protect themselves, they resist self-blame, and rely on medical explanations or ethnoetiologies to prove their innocence. Sometimes they resort to blaming the loss on the ill-will of others (Haws et al. 2010; Nations, 2008; van der Sijpt & Notermans, 2010).

**Effects on the family.** The effect of the loss on mothers’ psychological well-being, coupled with patterns of blaming/shaming, can disrupt her social functioning. The death of a baby frequently puts strain on the parents’ relationship, possibly as a result of different styles of grieving (most men grieve less intensely and for less time than women), the exhaustion of intense emotions following the loss, and deterioration in sexual functioning (Bennet et al., 2005; Zeanah, Danis, Hirshberg, & Dietz, 1995). However, over time the relationship may be strengthened by working through the loss together (Mekosh-Rosenbaum & Lasker, 1995).

Where childbearing is regarded as the primary role of women, reproductive failure may lead to the husband having an affair, starting a polygamous marriage or separating from his wife, even if she barely survived the event (de Kok et al., 2010). He may no longer feel obliged to contribute to her upkeep, especially if they were not in a formal marriage (Storeng,

Murray, Akoum, Outtara, & Fillippi, 2010). Failure to produce a live baby can render a woman vulnerable to emotional and/or violent abuse by her partner (Dyer, 2007).

Losing a baby impacts parents' relationships with their other children, especially those born after the loss. Unresolved grief can affect subsequent pregnancies and attachment to a new child, (Bennet et al., 2008; Robinson et al., 1999; Turton, Badenhorst, Pawlby, White, & Hughes, 2009). Because of this, women are often advised to wait for a year before falling pregnant. There is considerable evidence that symptoms of anxiety and depression are higher in those who conceive soon after the loss (Badenhorst & Hughes, 2007). Siblings of an infant who dies are affected by their own grief, as well as the grief of the family. Parents are often unable to support their other children because of their own distress (Bennet et al., 2008).

**Social implications of the loss.** Perinatal death leaves parents with a sense of isolation and dislocation from their social circle which exceeds that experienced in any other kind of loss (Bennet et al., 2008; Cacciotore et al., 2009). Theirs is a disenfranchised grief, for which contemporary Western culture has no established rituals (Neimeyer, Prigerson & Davies, 2002). There is no sense of how long a baby should be mourned, although the implicit message from the lack of social acknowledgement is that it should be done quickly and discreetly (McCoyd, 2010). Because few (if any) people apart from the parents have seen the baby, he or she is not socially salient beyond the immediate family. There is little sense of a person to be mourned, and the enormity of the loss goes unrecognised. Parents often find themselves at odds with their social grouping, and are required to process the grief alone (Abboud & Liamputtong, 2005; Cacciotore, 2010; Malacrida, 1999; Wing et al., 2001).

Studies in Africa reveal the profound social importance for women of bearing a child. Because social structures differ from those in the West, the specific effects of perinatal loss on the family and the broader social network cannot easily be differentiated. Pregnancy is "the utmost manifestation of relationships with a man and a woman and a child, but it also symbolizes wider kinship relationships, constituting the link between ancestors and future generations" (van der Sijpt, 2010, p.1775). Many women have little access to economic and social security outside of motherhood. Producing a viable baby ensures stability in a marriage or partnership, secures a woman's social status, raises her negotiating power (which is frequently negligible), and ushers her into adulthood. Pregnancy loss for a woman is the loss not only of a child, but also of her social identity (de Kok et al., 2010; Haws et al., 2010; Hough, 2010; van der Sijpt, 2010). The impact of perinatal loss on a woman's place in the social system can have far-reaching implications. Lack of social support and isolation can



result in intensified emotional distress, which can in turn increase isolation, resulting in long-term adjustment difficulties (Cacciatore, 2010; Malacrida, 1999).

**When coping skills and support fail: Prolonged Grief Disorder.** From the above discussion, it is clear that a stillbirth or neonatal death causes significant emotional distress and social disruption. However, not all parents are at risk of developing enduring adjustment problems. Following a wide range of modes and patterns of grieving, most individuals cope with the social and emotional disruptions precipitated by the loss, and return to normal levels of functioning within about two years. Some, however, experience ongoing grief and difficulty in functioning (Neria & Litz, 2004). They may be at risk for Prolonged Grief Disorder (PGD) (previously referred to as Complicated Grief (CG) ), characterised by “an inability to accept the loss, preoccupation with the deceased, confusion about one’s role in life, and loss of purpose and hope for the future” (Neimeyer et al., 2010, p.73). This is distinct from normal grief, PTSD or depression in that it involves the traumatic loss of a significant attachment figure. A high occurrence of PGD has been found among bereaved parents. It shares many features with PTSD disorder, is associated with poor mental and physical health, and can thus severely impair parents’ functioning (Bennet et al., 2008; Lichtental, Currier, Neimeyer, & Keesee, 2010; Neimeyer et al., 2002; Wheeler, 2001).

Several studies have tried to identify factors which influence the intensity and duration of grief in order to understand what puts parents at risk for these adjustment difficulties. However, findings have been mixed and a clear picture has yet to emerge. The following section discusses some of these research findings.

### **Factors Affecting Grief Outcomes**

Research investigating risk factors for poor grief outcomes has covered a number of areas of interest: pregnancy history, temperament, social support, the response of medical staff to the crisis, and (tangentially) religion. These will be outlined in some detail in this section. The role of meaning in grief outcomes has only been of interest more recently, and is discussed in the next section as a separate topic.

**Pregnancy history** . The effect of pregnancy history on grief and depression has been widely researched. An ongoing debate is whether later gestational loss results in more intense grief. Some studies found that late-loss parents experienced more grief symptoms (Bennet et al. 2008; Lin & Lasker, 1996; Theut et al., 1989), while others concluded that gestational age had no effect on grief (Elklit & Gudmundsdottir, 2006; Zeneah & Harmon, 1995). Shreffler et al. (2011) (N = 1284) found that perinatal loss in the first pregnancy (when women tend to be more invested than in later pregnancies) and recurrent loss are associated

with greater distress. These findings suggest that pregnancy history alone cannot predict grief responses: the inconsistencies in research results are likely to be indicative of the intensity of attachment to the baby, which may or may not be related to gestational age, number of pregnancies, or difficulty in conceiving.

**Personality characteristics.** The coping style of a mother when faced with negative life events could be an important predictor of grief outcomes, affecting her level of attachment to the baby, as well as her response to the loss. Some aspects of temperament have been correlated with increased distress: guilt-proneness, shame-proneness and dispositional envy (Barr & Cacciatores, 2008); maladaptive coping style (Bennet et al., 2008); and ruminative style (Michael & Snyder, 2005). All of these are considered to affect grief outcomes negatively because they hinder cognitive processing. An overview of several studies strongly suggests that pre-existing mental health difficulties, notably depression and anxiety (which are likely to be related to coping styles) make women more vulnerable to complicated grief responses (Klier, Geller, & Ritscher, 2002). On the other hand, characterological factors which predict better grief outcomes are: ego strength (Zeanah et al., 1995); hardiness (Badenhorst & Hughes, 2007) and emotional stability (Bennet et al., 2008). A stronger Sense of Coherence (SOC) (the ability to perceive a stressor as comprehensible, manageable and meaningful) in early pregnancy renders a mother less vulnerable to PTSD after pregnancy loss (Engelhard, van den Hout, & Vlaeyen, 2003). However, the influence of temperament on grieving patterns following perinatal loss is not generally well understood.

**Social support.** While coping *style* may be under-researched, the significance of coping *resources*, particularly social support, is well-documented. Often the parents' social system responds with ambivalence in the wake of perinatal loss, and parents report feeling isolated and misunderstood. Perceived lack of support has been associated with increased anxiety and depression (Cacciatores et al., 2009). Conversely, perceived presence of social support – from family, friends and institutions (such as hospital and church) - has consistently been found to be strongly correlated with positive grief outcomes, with family being the most important source of support (Abboud & Liamputtong, 2005; Cacciatores et al., 2009; Wing et al., 2001). The quality of the couple's relationship is a significant predictor of grief response, as parents rely on each other for emotional and practical support after the loss (Corbet-Owen, 2003; Wing et al., 2001; Zeanah & Harmon, 1995). A real or perceived lack of support from a partner has been significantly associated with increased grief symptoms (Brownlee & Oiken, 2004). Existing children also play a part in post-loss adjustment: parents who already have other children appear to grieve less than those who have no children. A

significant decrease in the intensity of grief often occurs after the birth of a viable baby subsequent to the loss. While children do not provide support per se, they are able to give the bereaved mother a purpose and a role to fulfil which may act as a protective factor against depression (Hughes, Turton, & Evans, 1999; Lin & Lasker, 1996; Obi et al., 2009; Theut et al., 1989; Zeneah & Harmon, 1995).

How exactly social support helps mothers to grieve has not been thoroughly explored. Talking about the baby may be an important source of support, especially considering the birth and death are usually experienced in isolation. Having conversations about a person who has died helps the bereaved to find social validation for the meaning of his or her life and death (Baddeley & Singer, 2009). Talking to other women who have had similar experiences and who offer optimistic views of the future may help to reduce negative affect. Practical support (e.g. financial assistance, providing meals) and gestures which demonstrate care seem to comfort the mothers and help to validate the loss (Abboud & Liamputtong, 2005). Social rituals (such as funerals) are thought to facilitate healthy grieving, but it is not clear if the rituals themselves or the social support which they express are more salient. No comprehensive research has been undertaken to examine this.

**Religion.** Religion has been found to be an important source of social support as well as a source of meaning-making following bereavement (Lichtental et al., 2010; Wortmann & Parks, 2008). Some of the mothers in qualitative studies described religious practices (such as prayer and reading from the Bible or Quran) and burial rites as comforting (Herbert, 1998; Kavanaugh & Hersherberger, 2005). However, religious coping with specific reference to perinatal loss has not been examined in any depth.

**Medical staff.** The response of medical staff powerfully influences both short term and long-term grieving (Abboud & Liamputtong, 2005; Covington & Theut, 1993; Wing et al., 2001). Even up to six years later, some parents still remember comments made by medical staff (Wright, 2011). Responses which diminish the loss, withhold information, or imply that the parents are in some way to blame engender a painful sense of powerlessness. Parents who feel they have been listened to, given as much information as possible, and been allowed to make their own choices, experience interaction with medical staff as supportive and helpful in dealing with their loss (Corbet-Owen & Kruger, 2001; Covington & Theut, 1999; Klier et al., 2002).

The medical establishment in low-income countries often seems ill-equipped to deal with parents' grief. Women report receiving inadequate information and being discouraged from talking about their loss. Some report feeling abused by staff (Modiba & Nolte, 2007;

Obi et al., 2009; Storeng et al., 2010). Obi et al. (2009) point to the difference between these women's experience and that of women in high-income countries, where grief is now widely recognised as clinically important and medical staff are much more sensitised to the emotional needs of bereaved parents. Haws et al. (2010) reiterate this: "acknowledgement and therapeutically discussing a pregnancy loss is predominantly a Western phenomenon and a recent one" (p. 1769).

### **Meaning**

As research on the effects of perinatal loss burgeoned in the West, practices and interventions to facilitate healthy grieving were developed. In the wake of this, efforts to apply contemporary grief theory to perinatal loss were made (Brownlee & Oiken, 2004; Uren & Wastell, 2002). The study by Uren & Wastell (2002) signified an important shift in research from analysis of symptomatology to exploring phenomenology. Using the three foundational concepts of attachment, trauma and meaning-making, they conducted a survey of 108 women to examine the psychological impact of perinatal loss. As they predicted, they found that Sense of Coherence (SOC), degree of attachment security, current search for meaning and the extent to which meaning had been found, were correlated with intensity of grief. The researchers conclude that "as long as the focus remains on overt grief responses, a deeper understanding of the phenomena particular to perinatal bereavement will not be achieved" (Uren & Wastell, 2002, p.305). Although research which considers grief from a meaning-making perspective has proliferated over the past decade, little of this has addressed perinatal loss specifically. An exception is a recent quantitative study by Shreffler et al. (2011) which examined the effect of mothers' attitudes to the pregnancy and loss on distress levels. Their results suggest that the "context of women's pregnancy and fertility experiences as a whole and the meanings they attribute to their pregnancies are crucial in shaping their psychological response to pregnancy loss" (p. 352).

Meanings of pregnancy are personal, formed on the basis of attachment to the unborn baby, as well as individual goals and identity (Corbet-Owen & Kruger, 2001; Dyer, 2007; Shreffler et al., 2011; Uren & Wastell, 2002). They are also socially constituted, context-specific and highly dynamic (Corbet-Owen & Kruger, 2001; Dyer, 2007; Scheper-Hughes, 1985; van der Sijpt & Notermans, 2010). This section explores, firstly, the relationship between attachment and meaning; secondly, possible personal meanings of pregnancy; and finally, differing social meanings of pregnancy.

**Attachment and meaning.** Robinson et al. (1999), Brownlee and Oiken (2004), and Uren and Wastell (2002) propose understanding perinatal loss within the paradigm of

attachment. Based on John Bowlby's theory of attachment and loss, both the attachment style of the parents and the nature of the bond which they form with the baby are regarded as crucial influences in grief outcomes, as they, to a large extent, define the meaning of the baby in the parents' lives (Brownlee & Oiken, 2004; Robinson et al., 1999; Uren & Wastell, 2002).

It is often assumed that the attachment bond is not very strong, as there has been little time to establish a relationship with the child (Uren & Wastell, 2002). However, maternal attachment begins long before birth, possibly even during the planning of the pregnancy. It is a complex process, based not only on physical events such as foetal movement, but also on the mother's conceptualisation of the infant and her imagined future as a mother (Robinson et al., 1999). The advance in medical technology which allows for seeing the foetus in utero and identifying the sex may add to earlier and more intense attachment to the baby (Robinson et al., 1999; Brownlee & Oiken, 2004). Shreffler et al. (2011) found that mothers who had strongly identified with a motherhood role, were committed to the pregnancy and attached to the unborn baby, experienced the highest levels of distress at pregnancy loss.

**Personal meaning of pregnancy.** Women may want children for a wide range of reasons: to take on a new identity (Robinson et al., 1999); to strengthen and secure the bond with her partner (Dyer, 2007, Robinson et al., 1999; van der Sijpt & Notermans, 2010); or for personal happiness and fulfilment (Dyer, 2007). For them, the loss of the baby is often accompanied by a range of secondary losses, such as the loss of an anticipated future, one's identity as a parent, and a sense of the world as a benevolent place (Corbett-Owen & Kruger, 2001; Wing et al., 2001). Conversely, unplanned pregnancies may evoke anxiety and despair in women, interrupting their life plans and curtailing their freedom. For them, pregnancy loss may be an ambivalent experience of relief and shame (Corbett-Owen & Kruger, 2001).

**Social meaning of pregnancy.** Expectations of motherhood vary across socio-economic and cultural settings. Social messages about pregnancy affect women even before conception: "these ideologies begin to have power from the moment one considers the possibility that one may become a mother at some time in the future" (McCoyd, 2010, p.137). With increased prosperity and medical efficiency in the West, parents have come to assume that they have a high level of control over reproduction. The death of a baby not only comes as a terrible shock, but is also construed as a personal failure (Badenhorst & Hughes, 2007; McCoyd, 2010).

In African society, children are a source of prestige, status, identity and economic power (de Kok et al., 2010; Dyer, 2007). In poor communities, children are needed to help parents with work, and provide for their old age (Dyer, 2007). There is a strong expectation

for couples to have children once they are married. Those who do not are criticised, mocked, and sometimes the women are maltreated (de Kok et al., 2010). The high value placed on having children means that mothers of low economic status often invest scarce resources into preserving their pregnancies, and put themselves at risk in order to give birth. The notion that poor women generally see pregnancy loss as a relief because there is one less child to support, is a fallacy which fails to recognise the social and emotional disruption which they suffer (Froen et al., 2011; Nations, 2008).

**Meaning and loss.** The meaning of a pregnancy is derived from a number of intrapsychic and contextual factors. Parents for whom pregnancy holds significant personal and social meaning and who have formed a strong attachment to their baby are likely to experience perinatal loss as traumatic. The loss frequently precipitates an existential crisis as they question previously held belief systems and try to find meaning in their bereavement. If meaning cannot be found, grief is likely to be more acute and more difficult to resolve (Cacciotore, 2010; Corbet-Owen & Kruger, 2001; Willick, 2006). The following section elaborates on this understanding of traumatic loss as a crisis of meaning, and explains how more recent theorists regard the grief process as reconstruction of meaning, rather than stages to be worked through.

### **Adjustment to Loss: The Role of Meaning-Making**

Traditional grief models see the grieving process as essentially intrapsychic, with the task of grief being to detach from the lost object. Grief “work” is considered a universal process necessary for healthy adjustment to loss. The grief trajectory has been variously described in terms of stages through which one moves until one reaches a period of resolution (Krueger, 2006). However, research has not convincingly substantiated these theories, and their basic tenets have been challenged in three key ways. Firstly, grief is recognised as being a social and interactional as well as an individual and intrapsychic response to loss (Neimeyer, 2000; Paletti, 2008). Secondly, grief theorists no longer consider it necessary to break bonds with the deceased person, but rather to find ways of recognising their ongoing significance in the life of the bereaved person. This takes place within community as the death is acknowledged, the deceased mourned and the “continuing bond with the dead person is validated and shared” (Klas, 2001, p.78). Thirdly, modern theorists call into question the idea of a predictable universal grief trajectory. Grieving is highly individual, and bereaved people react according to a number of personal and contextual factors. What may have previously been labelled pathological grief could, in fact, be a healthy and creative response

to loss which enables the bereaved person not only to return to previous levels of functioning, but also to experience personal growth (Neimeyer, 1999).

**Perinatal bereavement as a crisis of meaning.** In seeking a more comprehensive way of understanding grief, constructivist theory draws on attachment, trauma, and social-cognitive models of coping and adjustment to construe adaptation to loss as a process of meaning reconstruction (Gillies & Neimeyer, 2006; Lichtental et al., 2010). As discussed earlier, the nature of the attachment bond influences whether the baby's death will be experienced as traumatic or not (Uren & Wastell, 2002). When loss is traumatic, two key aspects of the self are challenged: one's sense of self-worth, and one's fundamental beliefs about how the world works. The bereaved may experience a lack of purpose, cohesion and sense of identity; and his/her core belief system may be severely disrupted (Davis & Nolen-Hoeksema, 2001; Gillies & Neimeyer, 2006; Lichtental et al., 2010). These "shattered assumptions" (Janoff-Bulman, 1992) elicit a crisis of meaning and the bereaved person is left with a frightening sense of meaninglessness and personal vulnerability (Neimeyer et al., 2010; Uren & Wastell, 2002; Willick, 2006). Cognitive theorists stress the need for people to re-establish a sense of purpose and control by integrating the new information from the trauma with old assumptions. Meaning-making attempts to address this challenge (Gillies & Neimeyer, 2006)

The death of a child of any age precipitates a crisis of meaning for parents (Keesee, Currier, & Neimeyer, 2008; Krueger, 2006; Lichtental et al., 2010; Wheeler, 2001), but perinatal loss is a very particular kind of trauma. It is a reversal of an assumed life path - parents are expected to die first; it is an abrupt shift from dealing with anticipated life to the reality of death; it is usually unanticipated. Often the birth and death experiences are physically traumatic, fraught with pain and struggle (Uren & Wastell, 2002; Willick, 2006). According to Bowlby (1969), "most of the most intense emotions arise during the formation, maintenance, the disruption and renewal of attachment relationships" (p. 269). When birth and death are almost simultaneous, these already intense emotions have the potential to be intensified even further. The extreme distress many parents experience at the loss of a baby can be understood in the light of this.

**Meaning-making processes: sense-making, benefit-finding, identity change.** Meaning-making is more than a cognitive coping strategy; rather, it is a multi-faceted reorientation to the world which takes place both consciously and unconsciously (Krueger, 2006). Neimeyer (2000) refers to it as "a predominantly tacit, passionate process that unfolds in the social field" (p.552). In attempting to restore meaning, individuals can assimilate their

loss into their pre-existing beliefs and sense of identity, constructing their understanding of the loss in ways that protect and retain core beliefs; or they can accommodate their loss by reworking their beliefs and identity. This may necessitate significant life changes, such as shifting to a community where these new values and ideas are validated (Neimeyer et al., 2010).

Common conceptualisations of the process of meaning-making include sense-making, benefit-finding and identity reconstruction (Gillies & Neimeyer, 2006). *Sense-making* addresses questions of how or why the death occurred. People look for concrete causes of the loss, as well as grapple with existential understandings within the framework of their existing worldviews (Gillies & Neimeyer, 2006; Davis, 2001). Studies have found sense-making to occur early on in the grieving process: bereaved people who can find meaningful answers to these questions six months post loss are likely to experience better long-term grief outcomes (Davis, 2001; Holland, Currier, & Neimeyer, 2006; Keesee et al., 2008). One of the most common ways in which parents make sense of the death of a child is through spirituality or religious beliefs (Lichtental et al., 2010). Those who cannot make sense of the death in this initial period struggle to do so, and may consequently embark on a painful and protracted revision of their worldview (Davis, 2001). Studies which have investigated meaning-making following the death of a child have consistently shown that parents find it very difficult to make sense of the death (Davis, Wortman, Lehman, & Silver, 2000; Keesee et al. 2008; Kruger, 2006; Lichtental et al., 2010; Wheeler, 2001.) Where the search for understanding is prolonged and seemingly irresolvable, distress is alleviated only through disengaging from trying to make sense of the loss (Davis et al., 2000).

*Benefit-finding* typically takes place months or even years later (Gillies & Neimeyer, 2006; Holland et al., 2006). It is not always possible to find sense in the loss; benefit-finding may in part be a way of dealing with the pain of these unanswered questions and may occur independently of sense-making. Commonly perceived benefits are personal growth, improved relationships, and a better understanding of life (Davis, 2001). Most common in bereaved parents is an increased desire to help and a greater compassion for others who are suffering (Cacciottore, 2010; Lichtental et al., 2010). The effect of benefit-finding on emotional adjustment appears to grow stronger over time, whereas sense-making only predicts emotional adjustment within the first six months (Davis, 2001).

Much benefit-finding appears to focus on changes in the self. Some theorists regard the primary function of benefit-finding as “maintaining or rebuilding a threatened sense of self” (Davis, 2001, p. 146). Despite these similarities, *identity change* seems to be a broader



process, which occurs both as a result of the adjustment of roles and relationships precipitated by the loss of a close attachment figure, and changed values, beliefs and ideas brought into being by meaning reconstruction (Gillies & Neimeyer, 2006). The death of a loved one may result in goals and ideals becoming unattainable (Davis, Hoeksema, & Larson, 1998). Parents invest their hopes and longings for the future in the life of a child. Death not only robs them of their role and identity as parents, but also of a hoped-for future. This is especially painful when the death is that of a first or only child, and parents struggle to find a different sense of identity and purpose (Wheeler, 2001). However, bereaved people who are able to find renewed purpose and meaning have greater life satisfaction, stronger reasons for living, more social support, and reduced distress over their loss (Gillies & Neimeyer, 2006).

A well-documented coping strategy following bereavement is to reappraise the loss as an opportunity for personal growth, including finding new goals, strengthening relationships and deepening maturity (Davis et al., 1998). In fact, the idea of self-transformation following bereavement seems to be quite consistent across cultures (Paletti, 2008). This process takes a long time, and is largely socially mediated (Cacciotore & Bushfield, 2007). As Neimeyer et al. (2002) put it, “the self is constituted and reconstituted in relation to an embracing social world, on which the individual necessarily draws and to which he or she repeatedly returns for validation” (p.239).

**Difficulties in meaning-making.** Given the interactional nature of meaning construction, it is unsurprising that those who experience a disenfranchised grief (such as perinatal loss) find it difficult to make meaning of their loss. Their isolation may increase their distress, which may, in turn, cause disruption in cognitive functioning which could hamper meaning-making (Keesee et al., 2008).

For some people, the loss may bring little or no disruption, because it easily assimilates into pre-existing negative meaning structures, reinforcing notions of the world as a cruel and unsafe place and themselves as unworthy or incompetent. Such individuals are likely to have disorganised attachment styles or have been subjected to ongoing trauma and stressors. Preliminary findings suggest that they are at great (possibly the greatest) risk for poor bereavement outcomes (Currier, Holland, & Neimeyer, 2009). It seems as though this world view may not be unsettled, but reinforced in a way that increases negative coping. For people who live in situations of continuous trauma and hardship (such as violence and poverty), it may be that their assumptive worlds are not shattered when someone dies, and they do not engage in meaning-making.

Bearing this in mind, in the final section of this literature review, reference will be made to some of the very few studies on grief which take into account context and, in particular, poverty.

### **Context: an Under-Researched Dimension**

Although many of the Western studies cited above pay attention to immediate context (such as pregnancy history, the parental dyad, social support), few give serious consideration to the effects of the broader context, such as political and social systems, cultural or ethnic practices and discourses, poverty and unemployment. What it means to grieve, or to recover from bereavement, may differ considerably across ethnocultural and socioeconomic circumstances (Paletti, 2008). Some qualitative culture-specific studies in low-income countries have addressed perinatal loss from a medical anthropological perspective. These give insight into how cultural and economic factors affect birth expectations and social outcomes, but do not explore the significance of these for personal grief processes. Two South African studies conducted with poor women who had lost children to HIV/AIDS (Rosenblatt & Nkosi, 2007) and been widowed (Demmer, 2010); and one with poor African American women who had experienced perinatal loss (Kavanaugh & Hershberger, 2005) suggest some of the challenges which confront them. All three studies found that their circumstances often made it difficult for them to grieve. Their experience of loss was as much about its economic consequences as about the death of a loved one. More than anything, these women needed to focus on everyday survival. The loss, alongside other intense negative life experiences “gave families more occasion to mourn, but depleted their capacity to do so” (Kavanaugh & Hershberger, 2005, p. 602). Opperman and Novello (2006), who examined the influence of context on Complicated Grief (or Prolonged Grief Disorder) in a small descriptive study conducted in Gauteng, identified an unsafe environment, conflict between the community and the bereaved person, loss of income and material security, and the medical community’s response to death as risk factors. In addition, they found that a stigmatised death in these circumstances compounded the difficulties. It may be that in developing countries, the stigma of perinatal loss is a much more prevalent barrier to grief than poverty, especially in settings where a woman’s purpose is regarded as primarily reproductive (Froen et al., 2011).

### **Conclusion**

It is clear from a wide range of studies that perinatal death deeply affects mothers psychologically and socially. Lack of social support and poor coping skills seem to increase their struggle to adjust, while the personal and social meanings of the baby’s death profoundly

influence the intensity of their grief. The death can consequently precipitate a painful disruption of fundamental meaning systems. Recovery following perinatal loss can thus be conceptualised as a process of meaning reconstruction, which takes place at an interpersonal, social and community level, informed by the socio-economic, cultural and historical context (Gillies & Neimeyer, 2006). Brownlee and Oiken (2004) comment on the dearth of research into contextual factors and grief, and suggest how poverty might affect the grieving process:

Despite the apparent role of social support in grieving, little attention has been paid to the influence of poverty on the grief process, even though it is to be accepted as a significant factor in affecting access to social supports...it is intricately linked to all experiential domains such as self-concept, regrets and hopes, opinions about others and thoughts about God. (p. 523)

Because meaning-making theories are more cognisant of contextual factors than the traditional grief theories which focus on intrapsychic processes, they seem to provide a useful framework for helping us to understand how mothers with limited access to the material and social resources which are available in high-income settings grieve for their babies following perinatal loss. At present, little is known about how such women construct meaning after perinatal loss, or what personal and social resources they draw on to do so. The current study hopes to address that gap.

The next chapter discusses the design of this study, and the methodology used for data collection and analysis.

### **Chapter Three: Methods**

The following chapter begins with describing the study setting and outlines the research aims. The study design is then explained, followed by an outline of sampling method and a description of the participants. Thereafter, data collection and analysis are discussed, and finally, ethical and validity issues are examined.

#### **Study Setting**

In 1994, the South African National Health System instigated a primary health care approach as a way of enabling disadvantaged communities to access health services. As a result of this, free antenatal and intrapartum care is offered to women who cannot afford medical aid. Most births in South Africa take place in clinics or in state hospitals. The health care system is divided into three tiers in the Western Cape. The first tier consists of seven Midwife Obstetric Units (MOUs) managed by midwives; the second is a secondary level hospital to which women are referred if there are complications in the pregnancy or delivery; and the third is the tertiary hospital where women with the most serious medical conditions are cared for (Abrahams et al., 2001). Because economic disparity in the Western Cape runs largely along racial lines, the majority of women who make use of state health care are Black and Coloured.

Most previous research has been conducted within predominantly urban Western settings or in rural areas in developing countries. Cape Town is a place where traditional and Western cultures intermingle, and where population movement from rural to urban areas presents many challenges related to social destabilisation and re-formation. While many findings from previous studies are relevant, the women in this study are situated in a particular socio-historic context of flux and economic precariousness. In a changing, pluralistic society where “discourses intermingle and sometimes clash, making competing demands on those persons immersed in them” (Neimeyer et al., 2002, p.238), individuals draw from different ways of viewing bereavement in the surrounding social discourse in order to understand their own situations. It is within this context that this study aims to examine how mothers make sense of and cope with perinatal loss.

#### **Aims of this Study**

The primary aim of this study was to achieve a greater understanding of how mothers with limited access to material and social resources make meaning of perinatal loss. The “disenfranchisement” of perinatal loss (Neimeyer, 2006; Willick, 2006) and the disempowerment which silences many women who live in poverty have resulted in the pain

of bereaved mothers seldom being fully recognised. This study aimed to explore what the loss meant for them, and how this meaning was derived.

Secondly, because disenfranchised grief is a form of empathic failure (Neimeyer, 2006; Willick, 2006), it is hoped that, in addition to intellectual awareness, a richer *empathic* understanding would be developed by presenting the narratives of individual mothers as unique and evocative accounts of loss. To this end, five narratives have been described in some detail.

Thirdly, it is hoped that this contribution to our understanding of the bereavement process will be used to inform health professionals and lay helpers working with bereaved mothers.

### **Design**

This study is situated within an interpretivist research paradigm, which is interested in how individuals understand and describe their experiences. It acknowledges the multi-faceted nature of reality, and assumes that people's interpretation of life events is influenced by many interacting factors (Henning, van Rensburg, & Smit, 2004). A narrative methodology was used, based on constructivist epistemology which holds that people use story-telling as a way of organising and arranging life events into a form that gives meaning and coherence to their lives (Riessman, 2008). The impetus to tell stories appears to be particularly strong among people dealing with death, loss and grief. This makes narrative a valuable tool in thanatological studies (Gilbert, 2002).

A narrative study is well suited to exploring the conscious and unconscious processes which construct meaning for a number of reasons. Firstly, narratives give access to explicit subjective experiences and understandings, as narrators explain and comment on unfolding events. Secondly, implicit meanings can be explored through in-depth analysis of structure and language, yielding information not available by other methods. For example, the way in which the experience is integrated into narratives through chronological placing and connection with other events has the potential to reveal what the central narrative meanings are, as well as how they are derived. Lastly, by listening for social and cultural voices within the narrative, it is possible to gain an understanding of both subjective experience and contextual influence. Thus it is a useful approach to explore how women engage in meaning-making following perinatal loss (Gilbert, 2002; Riessman, 2008; Willick, 2006).

### **Defining Poverty: Methodological Implications**

Fundamental to this study is a broad understanding of poverty which includes both material and social deprivation (Mabughi & Selim, 2006). The former refers to aspects such as access to food, clothing, water and electricity, type of housing, and working conditions; the latter refers to education levels, access to health services and information, and exclusion from support due to membership of a particular group. Furthermore, poverty is regarded as limiting individuals' options (de Kok et al., 2010) and constricting their "freedom to live the life they value" (Laderchi, Saith & Stewart, 2003, p.246).

A core methodological challenge was how to differentiate between "poor" and "non-poor" mothers. In many poverty studies, this is done pragmatically by using the receipt of public resources as a measure of low-income status (Laderchi et al., 2003, Kavanaugh & Hershberger, 2005). Based on this, the participants in this sample were women who used free state medical services. No other poverty indicators (e.g. income, housing, consumption) were formally investigated (although some of this information emerged in gathering demographic details), because a central concern of this study was the women's own analysis of their reality. A "participatory approach" (Laderchi et al., 2003) to understanding poverty was adopted, which limits the imposition of external criteria to determine what poverty is and focuses on participants' perceptions of what it means to be poor. In terms of data collection, these perceptions emerged spontaneously within the narratives, and in response to a reflective question ("if you had had more money, how would you have done things differently?")

### **Sampling**

The study was limited to women who have experienced either stillbirth or neonatal death. While there is still no consensus as to the differences in grief between early and late pregnancy loss and neonatal death (Bennet et al., 2008; Elklit & Gudmundsdottir, 2006), for the purpose of this study, stillbirth and early neonatal loss were assumed to be most similar in that the mother goes through the process of delivering a fully formed baby who could be viable (Willick, 2006).

Only mothers who had losses more than a year before the interview were approached to participate, because studies have shown that grief is still acute within the first year of loss, and interviews within that period could be very upsetting for the women (Lin & Lasker, 1996). In addition, the fact that a year or more had passed since the baby's death provided an opportunity to examine the evolving process of meaning-making as women looked back on the experience. There is some risk in retrospective studies that facts and details may have

been forgotten. However, the way that the mothers viewed their loss over time was of more interest than accurate recall of events (Gilbert, 2002).

Permission was granted by a state maternity hospital in Cape Town to access their records of neonatal deaths and stillbirths in order to identify potential participants. Six women were interviewed in 2010 as part of a Psychology Honours project which examined meaning-making following neonatal death among Xhosa-speaking women, and the remaining nine were interviewed in 2011. Recruitment for the project proved to be difficult for a number of reasons. A foundational challenge was explaining the purpose of the interview to women whose mother tongue is not English. It is possible that a Xhosa-speaking researcher may have found it easier to secure participants. Furthermore, poor women who have suffered perinatal loss can be defined as a hard-to-reach population (Penrod, Preston, Cain, & Starks, 2003) not only because of their emotional vulnerability after the bereavement, but also because their socio-economic situation means that they have limited access to landlines, cell phones are often shared, and they may have moved home at least once since the baby's death.

In 2011, of the 83 phone calls made, 13 were wrong numbers, 45 either went straight to voice mail, or there was no reply; only 25 resulted in conversations with mothers. Of these, four did not want to be interviewed because they thought it would be too upsetting, two had left Cape Town, and five could not speak much English. Of the 14 who agreed to be interviewed, two did not come because of unexpected work commitments, and three did not arrive for the interviews and could not subsequently be contacted.

### **Participants**

The sample consisted of 15 mothers who had experienced perinatal loss. Their ages ranged from 19 to 35 ( $M = 25, 8$ ). One of them had delivered two stillborn babies two years apart. One gave birth to twins, one of whom died at birth, and the other of whom lived for a day. The remaining 13 had babies who lived between 30 minutes to five days. Eight mothers had lost their first babies, five their second, one her third, and one her fourth. The length of time between the baby's death and the interview ranged from 12 to 30 months ( $M = 22$  months). Additional information is included in Appendix C.

In keeping with a study among African American parents in which low-income status was defined by their being recipients of Medicaid (state subsidised health care) (Kavanaugh & Hershberger, 2005), this study assumed that most women who use state health care would be from a low-income group. None of the women in the sample was in a position to afford private medical care at the time of the loss. However, their financial situations varied; some had a regular source of income and others had little or none. Nine of the women were

unemployed, one was at college, and six were in stable jobs. Of the unemployed women, one was supported by her mother, two by their grandmothers, three by their partners, and four had no regular means of support.

### **Interview Procedures**

**Interviewing.** Data collection was done through informal face-to-face interviews ranging from 30 to 64 minutes in length. Fourteen of the interviews were conducted in English and one in Afrikaans. The interview began with discussing and signing the informed consent form in English and (where necessary) in isiXhosa (see Appendix A).

A set of open-ended questions was designed as a guideline for the interview (see Appendix B). In reality, the interview unfolded as an interactive conversation, with participants articulating their stories in their own words and pursuing themes salient to their experience. They were given opportunity for extended narrative development with as little interruption as possible (Elliot, 2005). The reflective questions in sections five and six were asked once the initial story-telling had been completed.

In narrative research, it is understood that the narrative is created for the researcher, based on the participants' understanding of the purpose of the interview, and the personal interaction between them (Gilbert, 2002; Spector-Mersel, 2010). The interviewer's emotional attentiveness and the degree of reciprocity in conversation (which Ezzy (2010) refers to as the "emotional framing") proved to be as important as the scheduled questions in facilitating narrative construction (Riessman, 2008). This involved allowing silences and breaks in conversation; sensitivity to the levels of distress of the participant and being prepared to shift the discussion when the emotional content seemed to overwhelm her; and being open to material which was not obviously relevant to the research topic, but was clearly important to the woman.

**Venue.** In interviews which deal with sensitive topics such as death, venues can make a significant difference to the comfort or discomfort of the participant. Two women were interviewed at work, with their employers' permission, five at their own homes, seven at the Maternity Hospital (MH), and one at the tertiary institution where she is a student. Two of the interviews conducted at home were frequently interrupted by children, which prolonged the interviews, but did not seem to compromise them. One woman (Anne) asked if we could move to the car, as she did not want her mother to hear what she had to say. The women who were interviewed at the Maternity Hospital (MH) had been offered an alternative venue, but indicated that they preferred to meet at a familiar place where we had the privacy of an office. The venue was undoubtedly evocative for them. Some of the mothers were visibly moved as



we walked past the ICU, as the sight of the babies clearly brought back memories. The interviewer paid close attention to their responses, and offered to move to another venue, but the participants assured her that they would be alright. Two of them later expressed that it had been “good” to be back; and two of them had the opportunity to discuss unresolved questions about their loss with paediatricians at the hospital.

**Recording and transcribing.** All interviews were recorded with the participants’ permission and transcribed verbatim. Because a transcription is always only a partial representation, brief field notes were taken during the interview, observing non-verbal aspects of the interaction, and these were later noted in the transcripts (Mason, 2005).

### **Data Analysis**

As this research is interested in exploring unique as well as common aspects of meaning-making, both structural and content analysis techniques were used. The analysis plan was guided by three foundational understandings of narrative: firstly, that individuals are socially and culturally embedded and draw on available discourses to construct their narratives; secondly, that individuals have unique linguistic repertoires and ways of organising subjective experience; and thirdly, that the interviewer consciously and unconsciously co-creates the narrative. Thus the analysis needed to pay attention to contextual influence and individual meaning, as well as interrogate how the creation and interpretation of the narratives were influenced by personal positioning and bias.

Data analysis was undertaken in three phases, incorporating suggestions from Fraser (2004), Franzosi (1998), Riley and Hawe (2005), and Zilbar, Tuval-Maschiach and Lieblich (2008).

The first phase focussed on the structure of the interview. The narrative was divided into numbered lines, based on meaning units which were either sentences, clauses or phrases. These were kept fairly short so that they could be easily read and accessed. The text was then divided into narrative segments, centred on an event, theme, or interaction. Each segment was named using either a significant phrase from the text, or an appropriate heading. Segments were then plotted on a timeline as a way of investigating how the narrator has organised her story. Preliminary ideas as to the purpose of this structure were noted. Detailed notes were made of the initial impressions gained from the reading, including identifying words, phrases or themes that had been repeated. Finally, I reflected on my role as co-constructor: how actively did I direct the narrative? Where did it flow, or seem stuck? How did my affective response (expressed or unexpressed) influence narrative development?

The second phase concentrated on more in-depth examination of the narrative segments. Segments were identified as being central or peripheral to the narrative. The language structure of the most salient segments was examined. References to context – either direct or emerging in other voices within the story - were noted in order to gain insight into how the narrator was positioning herself in relation to her environment. Finally, I reflected on how personal bias could be affecting my understanding, and how the participant might respond to my interpretation.

At the end of the first two phases, a synopsis of each interview narrative was written as a way to preserve the uniqueness of each participant's story before progressing to the third phase (see Appendix D). Where possible, phrases and words from the interview were used to construct the synopsis.

The third phase drew together commonalities and differences between the narratives, both in content and structure. I reflected on reasons for choosing those particular themes. Given the limited scope of this study, it was necessary to discard some and focus on others. This choice was made on the basis of previous research, centrality to the research question, and how often the theme emerged.

### **Ethical Considerations**

All participants signed an informed consent form which took into consideration the risks and benefits of participation, promised to pay transport costs to the interview, and assured them that their material would be kept confidential. Pseudonyms have been used for the women, and the babies' names have been used with their mothers' permission. However, ethical issues around bereavement research are more complex than is evident in the contents of the informed consent form. Additional issues arose out of the fact that the participants were poor women dependent on state medical care, the open-ended nature of the interviews, and my complex position as researcher, trainee clinician, and bereaved mother.

**Poverty, power and vulnerability.** Participation was voluntary, but there was some concern that the women would feel obliged to take part in the interview because their names had been accessed through a state institution. In the course of the telephone call inviting them to participate, they were assured that they did not have to do the study. A text message confirming the appointment was sent to them the day before the interview. In this, they were reminded that they were not obliged to participate and were requested to let the interviewer know if they had changed their minds. The women were not offered payment for participation, as it was felt that this might be experienced as coercive. They were, however, given a gift to thank them for taking part.

Although the women's transport costs to the interview were paid when they arrived at the venue, three of them had to borrow money to get to MH. This was an unanticipated difficulty, which may also have impacted access to follow-up counselling. The services of a counselor (a social worker at MH) were offered to any women who wanted help in dealing with distress arising from the interview process. None of the participants took up this offer. The reason for this is not clear, but it is possible that some could not have afforded transport to return for a counselling session.

The decision to work within a collaborative paradigm was as much an ethical as a methodological one (Valentine, 2007). As a white middle-class woman conducting research among previously disadvantaged women, I was aware of the power differentials which might influence the interview process. The women may have been inclined to tell me what they felt I needed or wanted to hear; or I may have patronized them or romanticized their stories (Hoshmand, 2005). The method of data collection (described above) took into account both the nature of good narrative data and concern for the mothers' well-being. Consequently, care was taken to conduct the interviews in such a way that the women felt neither judged nor coerced.

**Risks and benefits.** A particular concern was that talking about the loss would harm the mothers emotionally. Although every effort was made to explain to the participants what to expect of the interview, there can never be absolute clarity as to what they are consenting to in an open-ended interview. Conversation may evolve in ways neither researcher nor participant had anticipated (Saville Young, 2009; Smythe & Murray, 2000). Researchers who are also clinicians (or, in this instance, a clinician-in-training) face particular challenges in facilitating disclosure when interviewing on sensitive topics. The boundaries between the two roles may blur, or they may conflict (Long & Eagle, 2009; Smythe & Murray, 2000; Willick, 2006). While the listening skills of a therapist are undoubtedly helpful in a research context, these may serve to take the interview to a level not anticipated by the participant, and the researcher needs to guard against such intrusions. For example, the interviewer could offer interpretations that bring to light material which cannot be adequately processed within the restrictions of the research project, thereby exposing the participant to potential harm (Long & Eagle, 2009; Willick, 2006). Furthermore, there may also be times when the clinician-researcher judges the participant to be in need of intervention, and is required to weigh clinical ethics against research ethics (Long & Eagle, 2009).

The parameters of this study provided for the option of counselling as a follow-up intervention. This was offered to all, but strongly recommended to two of the participants;

however, none of the women pursued this. Two others, who showed particular distress at not knowing the cause of their babies' deaths, have since met with pediatricians to discuss this at my suggestion. One of the women (Vuyokhazi), who had no mementoes of her baby as her boyfriend deleted her photograph, was given her baby's footprints which were still in her hospital folder. This was done on the basis of her extreme sadness at losing the photograph, and the well-documented evidence that mementoes provide comfort to bereaved mothers. These interventions may have moved beyond the scope of the interview, but they were deemed ethically appropriate ways of responding to the women's distress.

Contrary to the expectation that discussing bereavement may be harmful to participants, grief studies have found that research interviews often give people therapeutic space to talk about their losses which they do not find elsewhere in their lives (Gilbert, 2002; Valentine, 2007; Willick, 2006). The skills which a clinician brings to an interview enable her to offer empathy and containment (Long & Eagle, 2009). In this study, 13 of the 15 participants cried during the interview. However, an expression of grief or distress does not necessarily equate with "harm", but can be cathartic and ultimately beneficial (Saville Young, 2009). Nine of the women later expressed that it had been helpful to talk about their babies' deaths. In addition, two of the women in this study said they were glad to do the interview as they saw it as a way of helping others. Similar sentiments were expressed by participants in Willick's (2006) study.

**The challenges of an insider's perspective .** Having had a personal experience of perinatal loss (in 1990) heightened the possibility of empathic listening and insightful questions, but it also posed the risk of my allowing pre-existing emotions and responses to intrude on the interview. Researchers with an insider's perspective are possibly required to engage even more rigorously with self-reflection and openness about choices made throughout the research process (Valentine, 2007; Willick, 2006). During the interviews conducted in 2010, and the first two conducted in 2011, I followed Willick (2006), in mentioning my personal experience briefly at the beginning of the interview as part of explaining the purpose of the research. One of the motivations for doing this was to try to bridge the significant demographic differences between us. However, it was unclear whether this disclosure helped or hindered the interaction. The decision not to disclose in subsequent interviews was based on the need to create a distance from memories of my own experience, which were being evoked by an accumulation of emotive interviews. I did not want my capacity to listen to the participants to be compromised by bringing my own loss into the conversation.

## The Validity of Narrative Studies

Narrative inquiry is situated within an epistemological and hermeneutical paradigm which considers knowledge to be partial and contingent. In practice, this means that ideas are presented as “tentative, circular and multiple” (Fraser, 2004, p. 183) rather than as certainties (Fraser, 2004; Polkinghorne, 2007; Hoshmand, 2005). The validity of a study rests not on proving results to be “true”, but on constructing a *trustworthy* and *credible* representation of the participants’ social realities (Creswell & Miller, 2000; Polkinghorne, 2007).

*Credibility* is established by presenting well-grounded, plausible arguments which persuade the reader of the integrity of interpretation. In this study, arguments are consolidated by supporting the analysis with rich descriptions and detailed reference to the text, using participants’ own words as far as possible (Creswell & Miller, 2000; Polkinghorne, 2007).

In order to fulfil the criterion of *trustworthiness*, three processes were undertaken. Firstly, the researcher engaged in reflexivity throughout the research to become aware how personal history, subjectivity, and theoretical stance were affecting data collection and, later, analysis (Creswell & Miller, 2000; Willick, 2006; Zilbar et al., 2008). This was done through journaling after interviews, and engaging with the structured reflexivity questions forming part of the analysis procedure. Secondly, this study cultivated deliberate awareness of how the narrative data were affected by researcher and narrator agendas and intersubjectivity, recognising that a different interviewer or interviewing style may have accessed information and perspectives not available within the limits of this research project (Polkinghorne, 2007; Willick, 2006). Thirdly, by engaging repeatedly with the text, and deliberately questioning interpretations made at each stage (which Creswell and Miller (2000) term searching for “disconfirming evidence” (p. 127)), it was hoped that the analysis would align as closely as possible with the meanings of the participants (Polkinghorne, 2007).

The narrative “truth” which this study describes is acknowledged to reflect a specific and unique set of interviews. These results are not intended to be generalised. However, presenting such context specific truths as “tentative, circular and multiple” (Fraser, 2004, p. 183) does not reduce their validity, but can open up the possibility of further interpretation and other avenues of research.

The following chapter presents a comprehensive discussion of the results that emerged from the analysis of the participants’ narratives.

## Chapter Four: Analysis and Discussion

This chapter is divided into three sections. The purpose of the first section is to describe common ways in which the women experienced their environments in order to provide a backdrop against which their meaning-making processes can be understood. The second section discusses common meanings and meaning-making patterns. The final section describes how the women's sense of agency and social support affected their capacity to make meaning of the loss within their particular contexts.

### Describing the Context

The loss of a baby inevitably takes place within a multifaceted context, and what is happening in the rest of the mother's life has significant bearing on how she makes sense of her loss (Gillies & Neimeyer, 2006). Women living in poverty deal with many stressors which have the potential to intensify the traumatic nature of pregnancy loss, and hinder the process of recovery. All the participants in this study referred in differing degrees to the pervasive difficulties of their lives. These are described below, with reference to medical services, education, work, accommodation and lack of money to meet their needs. In different ways, these factors limited their options in coping with the loss.

**Medical Services.** The inadequacy of medical response to perinatal loss has consistently been found to increase parents' distress (Cacciotore & Bushfield, 2007; Covington & Theut, 1993) and this is possibly more pronounced in low-income settings due to factors such as staff shortage and lack of training (Modiba & Nolte, 2007; Obi et al., 2009; Storeng et al., 2010). The experiences of some of the women in this study clearly contributed to the trauma of their loss. All but two were dissatisfied with the care they received. Of the remaining thirteen, nine blamed either the Midwife Obstetric Units (MOU) or the Maternity Hospital (MH) for the deaths of their babies.

They described waiting for long periods of time, even while in labour, because of the number of women needing attention.

You have to wait there. They don't care if the pain is high or what, they will tell you you must wait there; they are busy with someone else, where is your pain? (Nosipho)

Probably the fifth or sixth time I went back there again, and they kept me there for a while, and eventually when they could help me, because there are a lot of women who come and give birth there, and there are not enough beds and things like that, eventually when she saw me, so she told me the baby had messed inside of me. (Anne)

Ambulance services, used to transport women in crisis labour to MH, are regarded as very slow. Bongeka chose to walk to her cousin, whom she knew could borrow a car, rather

than wait for an ambulance. Jean gave birth in the ambulance, and Nosandla waited for one for almost five hours.

Some of the women questioned the competence of the medical staff. Anne, Bongeka and Nontombi were told they were not in labour, even though they were sure that they were. Bongeka went to the MOU after her membranes ruptured when she was five and a half months pregnant. She recounted the response of the staff:

I told them what happened and they didn't even believe me. They just look at me and say there's nothing. They can't see anything. And they were speaking in Afrikaans and laughing as if I'm telling lies.

Ayabonga, Nontombi and Zodwa wondered if the delay in recognising that something was wrong with their babies led to their deaths. Four of the women gave birth with no medical staff present, and expressed, on different levels, feeling abandoned. Nontombi said, "They didn't even help me. I gave birth on my own. And they didn't even care."

The expectation of the care at MH was much higher than at the MOUs, and the mothers were bitterly disappointed when nothing could be done for their babies. Ayanda and Zanele, who delivered premature babies, could not understand why they were not incubated. Lack of understanding about why their babies died exacerbated the women's distress. Although eight of the narratives gave accounts of doctors trying to explain to the mothers what had happened to their babies, they did not always understand what they were being told, and five of them expressed anger towards the medical staff for not giving them adequate explanation. The reason for the lack of understanding was not clear: it could be that they did not grasp the medical terminology, or that they were unable to listen properly because of their emotional distress. Despite general dissatisfaction with medical care, four of the mothers specifically commended the staff at MH for their kindness, and all of them appreciated the mementoes (photographs, handprints, footprints) which the ICU gave to them.

Apart from Ntombekhaya, all the women said that if they had money, they would choose private health care because it is perceived to be better than state health care. However, their traumatic experiences cannot be blamed on the medical services alone. Some of the women seemed ignorant or negligent of their own medical needs and did not look for help when they needed it. The reasons behind this are not clear, but may have to do with poor levels of education or pre-occupation with other difficulties.

Ntombekhaya and Nosipho did not realise they were pregnant and so did not book into a clinic.

I was not feeling well, but I didn't take it seriously. You know, seeing that I was getting pregnant for the first time, I didn't know nothing about pregnancy.  
(Ntombekhaya)

Jean did not book because she thought everything was fine. Nosandla, Jean, Ayabonga and Nosipho did not recognise they were in labour until it was far advanced, and so compromised their babies' chances of survival. Similar patterns have been identified in other studies among low-income groups (Gilson & McIntyre, 2007; Kavanaugh & Hershberger, 2008; Lawn et al., 2005).

**Accommodation and social support.** Social support has consistently been defined as one of the most important predictors of grief outcomes (Bennet et al., 2008; Cacciotore et al., 2009) and fundamental in the process of meaning-making (Gillies & Neimeyer, 2006; Klas, 2001). Where this is destabilised (as a result, for example, of overcrowding, urbanisation and frequent population movement), women are deprived of a key element needed for reconstructing meaning after bereavement.

Where the women lived impacted their access to health care, and the people they lived with largely determined the quality of support given during the pregnancy and following the baby's death. Seven of the women had very stable housing situations. Six of them lived in two-bedroomed houses and one in a three-bedroomed flat. These all had electricity and water. The maximum number living in one house was five, and the minimum two. Two of the women have lived in the same house all their lives. Generally, they spoke of being adequately supported both financially and emotionally by their families.

Ayanda, Jean and Nontombi lived in environments characterised by conflict during their pregnancy and straight after the loss. Ayanda (whose mother died of AIDS when she was very small) lived with her aunt and cousin. She described how her aunt used to hit her and make her do housework even when she was heavily pregnant. She left about six months after her baby died, and went to live with six other adults in a backyard dwelling. Jean was living with her husband, parents, and two children in a backyard dwelling attached to her parents-in-law's house. They moved there from Kenilworth after her father was retrenched. She frequently fought with her mother-in-law (who hit her on occasion) and wondered if the conflict had caused her baby's death. Nontombi lived with her stepfather and three siblings in an informal settlement. He was often drunk, hostile, and verbally abusive. Ayabonga and Vuyokhazi had moved often, and so had little social support. At the time of the interview, Nosandla lived in the southern suburbs with her husband, but sometimes went back to the



township where she had grown up to stay with her mother as she felt lonely. Bongeka and Vuyokhazi came from the Eastern Cape where their close family members still live.

**Education.** Education, regarded by most of the women as a way to a better life, is severely disrupted by an unplanned pregnancy. The death of the baby, which one might assume would make it easier for the women to go back to studying, does not necessarily do so. The depression and social isolation which often come in its wake make it difficult for them to re-integrate into the education system.

Two of the women dropped out of school as a result of their baby's death and two left college. Ayabonga and Nosipho left school, not because of being pregnant (Nosipho has an older child, and continued her education uninterrupted throughout that pregnancy), but because of feeling so unhappy at school after the loss that they were unable to continue.

When I lost my baby, I didn't want anything. I just wanted to stay at home alone, so just leave school. (Nosipho)

(I dropped out) because of the hardness I had. Because when I am in school, I just feel tired, tired, tired, and bored, because every time I think about my situation, I feel to cry in the class. (Ayabonga)

Both regretted this. Nosipho's grandmother (who brought her up because her parents were dead) was bitterly disappointed as she had hoped that Nosipho would become educated so that she could support herself and her younger brother. Ayabonga said, "I had to drop out because of my situation, but I knew it was wrong to drop out."

Anne left college when she was pregnant. What was particularly hard for her was that she was the only one of her siblings to finish school and she felt that she had let her mother down. Although she could have gone back as she had no baby to care for, she did not feel like it, and after that it was not financially possible as her mother had stopped working. Vuyokhazi, on the other hand, resolutely returned to college three days after her baby's death, which she saw as a way of getting over her loss. However, she was not able to pay her fees and so could not pursue her studies. Bongeka, who was not studying when her baby died, decided to do so as a way of "filling the space" left by his death. She was passionate in her explanation of how this had helped her.

...then this Tech took me. That's when I started to be like myself again...there is still this space now, but I think school really helped me to be busy with something after that...

**Employment.** Work featured in the narratives as a factor which affected the pregnancy outcome, or as something which was disrupted by the pregnancy and loss, or as a means of recovering from the loss. All the women spoke about earning money with a sense of

urgency, although for those who had no one to support them (Ayabonga, Vuyokhazi, Nonkululeko), this was coloured with desperation. Nonkululeko's situation was particularly difficult as she had other dependents. She blamed her twin babies for her job loss: she stopped working when she was pregnant, and by the time she recovered from the birth, her former employer no longer needed her. She had experienced multiple difficulties: her older child had a baby while still at school; her boyfriend left her after the babies' deaths; she struggled to support her two children. Her grief seemed bound up with the distress of unemployment.

I get the babies and that is something that caused me to be without a job is those babies. Now I don't have a job and I don't have those babies. Everything is fucked... If I'm gonna get a job, I think everything will be fine. (Nonkululeko)

Ayanda and Ntombekhaya found it difficult to work after their babies' deaths because of depression; Nosandla, Zanele, Naziema, Norma and Nontombi found going back to work helpful because it kept them busy and stopped them thinking too much about the baby. At the time of the interview, Anne, Ayabonga, Nonkululeko and Vuyokhazi were all struggling to find work.

There has been no research done on employment and grief. This study suggests that work can play an important role in facilitating reconstruction by providing hope and purpose, or in hindering it by placing too much stress on the bereaved mother. Unemployment seems to contribute to the debilitating sense of helplessness which women experience after the loss of a baby, and increases anxiety associated with being unable to envisage a worthwhile future for themselves.

**Lack of money.** Not having money affected the women in other important ways. Five of them were unable to pay for a proper funeral. Nontombi's words give an idea of how painful this was for her:

...sometimes I see people visiting their babies' graves and then I think, if I had more money and buried my own child, maybe every time I miss her so much, I should go and talk to her and just visit.

Bongeka borrowed money from her brother to pay for the hospital to bury her baby, as she could not even afford that small amount (R200). Nosipho's boyfriend and grandmother borrowed money to bury her baby. It took them over a year to pay this back. Borrowing money was a theme which emerged often in the women's narratives. Jean and Bongeka both borrowed money for a single visit to a private doctor. Ayabonga and Vuyokhazi had to borrow money to come to the interview.

There were allusions in the women's stories to how being so financially dependent on others affected their relationships, and how the babies' deaths complicated this. Before the

birth of her baby, Ayabonga was able to borrow money from people in her community without too much difficulty; after having a baby, she was considered an “adult” who needed to support herself. Vuyokhazi thought that her boyfriend broke up with her after her baby died because she had no money (“he always said I demand a lot”).

An issue which complicated the women’s grief was the acknowledgment that had the baby survived, their financial situations would have been even more difficult. There was a hidden sense of relief at the death which was not allowed to be given voice apart from in oblique ways. Nosipho expressed anger against her boyfriend for losing his job on the day the baby died:

I was angry because if the baby was alive, he was not, he was not, he was not going to survive (4) we were not going to have the money to buy things for him.

Anne broke up with her boyfriend a year after her baby died because he wanted another baby.

The reason I broke up with him was because I can’t have another baby. I cannot afford to have another baby. The baby was a mistake - not a mistake, but it wasn’t planned at all. How can you expect me to have another baby? I don’t have a job. I have nothing.

**Living with multiple losses.** The narratives give a strong impression that the participants regard life as fundamentally difficult. The environments in which they live are “rough” (Zodwa), there are drug dealers and gangsters around (Anne), work is scarce, medical care is inferior, and they have to work hard to establish a future for themselves. Many had experienced the deaths of siblings and parents. Twelve of the 15 women had not had fathers involved in their upbringing. Six of them had lost mothers. Given how important mothers were in helping the other women recover after losing their babies, this loss is very significant. Despite being accustomed to living with loss and hardship, the mothers all experienced the death of the baby as an enormous shock, and not as an unsurprising event (as de Kok et al. (2010) and Opperman & Novello (2006) suggest).

**Context and the limitation of options.** The above descriptions give an idea of how the mothers’ options in coping with the loss were limited by their contexts. Medical facilities did not give them the level of health care they expected, and they struggled to understand the explanations given to them. The disruption of social systems robbed three of the women of support needed for the recovery process, and five of them were unable to engage in funeral rites which would have helped in their grieving. Choices with regards to education and work – aspects which may have engendered hope for the future – were limited by scarcity of jobs, and psychosocial and financial difficulties in continuing schooling. The women’s external situations did not readily provide comfort or foster optimism. Meaning-making was thus a

necessary survival tool to overcome the disruption of the loss and the ongoing difficulties of their lives.

### **Meaning-Making**

With the exception of Vuyokhazi, all the mothers seemed to engage consciously in meaning-making, in ways similarly described in much of the literature. This involved finding causal understanding for the death, making existential sense of what happened, and integrating the stressful experience into their identity and goals (Park, 2010). There was little evidence of another common meaning-making strategy, namely benefit-finding, but this may be a function of the length of time since loss ( $M = 22,8$  months) as benefit-finding is typically a secondary process (Davis, 2001). Two additional patterns emerged: affirming the meaning of the pregnancy and establishing the baby as a person to be mourned.

#### **Pregnancy, motherhood and identity.**

**Pregnancy.** The meanings attributed to pregnancy and childbearing significantly affect the meaning of the loss (Shreffler et al., 2011). Eleven of the fifteen women in this sample had unplanned pregnancies. A previous study in the Western Cape (Corbett-Owen & Kruger, 2001) suggested that the loss of an unplanned pregnancy can result in relief and ambivalent grief. The findings of this study show that most of the women (with the exception of Anne) accepted and invested in their unplanned pregnancy, formed an attachment with the baby, and experienced the loss as profoundly personal. The ways in which the women attempted to come to terms with their pregnancies reveal complex social and personal understandings of fertility and childbirth.

For women who were in stable relationships with their partners, the pregnancy (planned or unplanned) was accepted and welcomed. The fathers were pleased and involved. The pregnancy was seen as an extension of their relationship.

When I was pregnant, I was feeling very happy because my husband and I were staying together. Even he was excited that we were going to have a second child. (Nosandla, planned pregnancy)

Noo, no, it wasn't a planned pregnancy, but that time I was living with my boyfriend. He stopped drinking and he stopped smoking. He saved up money and stuff. (Zodwa)

I was very surprised when I got pregnant. It was ok, it's fine. It's not going to be a problem because I was already staying with my aunt by that time and the baby's father was working. (Nontombi)

Being in a stable relationship, with regular income and support seemed to make it easier to accept the pregnancy.

Those women (Zanele, Ntombekhaya) who did not have good relationships with the fathers, but had very supportive families were fairly easily able to come to terms with having a child.

As time goes by, I realise that, ok, fine, this is it now, I'm pregnant. So I had to adjust and live with it and make something out of it. (Ntombekhaya).

The women who were less financially and socially secure found other motivations to cope with the unexpected pregnancy. Bongeka was "older" (27) and was pleased at the idea of having a child. Nonkululeko thought that she would be "better than her mother" who had had only two children.

Many of the women demonstrated a high level of investment in the pregnancy (where investment is understood as "the tendency to be psychologically attuned to a role" (Shreffler et al., 2010, p.343)), buying clothes for the baby despite financial constraints (Nontombi, Ayabonga, Nosipho, Nosandla, Zanele), and attending the clinic regularly (all except Ntombekhaya, Jean and Nosipho). This is in keeping with Froen et al.'s (2011) comment that poor women often invest precious resources into their pregnancies.

In different ways, the women described how they formed strong bonds with their babies soon after birth, in most cases consolidating attachment that had begun during the pregnancy.

I get to miss her sometimes. Because you know, even if it was like one day or two, there is that connection between the mother and child. (Ntombekhaya)

I wanted that baby. It was *my* baby. (Nontombi)

I had three days with him. And yes, I felt it's still my son – it's still my child. (Naziema)

He's in my mind. There wasn't much time for me to bond with the baby ... You never lose knowledge of that baby. The baby is always on your mind. (Norma)

Three of the women expressed deep dismay at being pregnant. Nosipho already had a child and was trying to complete her schooling. She denied the reality of her pregnancy and did not book into a clinic. Two of them considered terminating the pregnancy. Ayabonga's boyfriend threatened to report her to the police if she had an abortion. She persuaded herself that she would cope with having a baby, and later came to regard her child as being very important in alleviating her loneliness. Anne (still at college) was persuaded not to terminate the pregnancy, because it would be "unfair" to her boyfriend.

I was just not happy and I started using drugs in order to (5) I just wanted to get rid of it – of the child.

Later on, she reflected:

After he was born, I felt so different. I thought, this is my child now. You know, that immediate love you have for your child.

Her grief was complicated by her initial rejection of her pregnancy and guilt because her drug-taking may have caused his death. Her boyfriend wanted to have another baby, which she suspected was partially out of jealousy and as a way of binding her to him. Because she wanted to get on with her own life, she eventually broke up with him. The pregnancy has a similar role in Bongeka's story: she was bound to her abusive boyfriend because they were both invested in the pregnancy, but left him a few months after the baby died.

***Motherhood and identity.*** Underlying these personal responses to pregnancy were social meanings around children and motherhood. Children, whether planned or unplanned are seen as a gift from God, and women have a responsibility to nurture them as part of their natural role.

If you are supposed to get a baby, you are supposed to get it... it's only God who knows why. (Nonkululeko)

I was shocked at the time, but just accepted it so I said, okay, it happened. There's nothing I can do because I don't believe in abortion. I think it's cruel because you were given a child and you ought to give a chance to the baby. (Zanele)

Nosandla's description indicated a powerful feeling of responsibility towards her child, which took precedence over her own need for rest.

Because the nurses said that if I want to go and rest, I can go and rest. But I say I can't go and rest whereas my child is here. I can't be far from my child. I have to give him that support that he can feel I'm here with him. (Nosandla)

Motherhood seems to be regarded as an initiation into full womanhood: women who do not have children are incomplete. As a result, the death of a baby deprives a woman of her identity and role, putting her in the confusing position of being a mother with no one to mother. It is difficult to go back to being a carefree woman with no responsibilities.

The mentality of being a mother never went away, even though I didn't have a child... maybe I became responsible in the way of thinking that I am a person's mother. I changed from the person I was, because before that I was reckless. I was a drinking girl, going out all night partying. And after my daughter, that all changed. (Zodwa)

Ayanda negotiated this ambivalent transition into motherhood by defining herself as a "single mother" despite the fact that after two pregnancies, she had no live children.

The gap left by the baby's death, closely bound to personal identity, is a difficult wound to heal (Cacciotore et al., 2009; McCoyd, 2010; Theut et al., 1989). Bongeka spoke of the "space for him in myself". Seven of the women expressed the importance of having another baby. Of these, four had no children prior to the loss. Three of them have had

subsequent children; one was pregnant at the time of the interview, two were planning to fall pregnant and Naziema wanted to have a reverse sterilisation so that she could have another baby. Zanele evocatively summed up this dilemma:

The fact that you have lost a baby pulls, pulls you apart. Something in you goes with the baby. And, probably, I think I am complete now. It comes back when you have other babies. (Zanele)

Some of the women sought to recreate that identity and purpose through their relationships with their own children, or with others' children. Nontombi, Zanele, Naziema, Naomi and Jean said they had to "be strong" for their other children.

I couldn't really break down because I have my other three children that I need to think of, so I had to keep strong for them... My son has brought me through a lot as well because I'll constantly look at him... I always look at him and I think to myself, I've got you. I've still got you. (Naziema)

I tell myself, I have to be strong. I have to work and provide for this one (*her son*). (Nontombi)

Bongeka and Anne found comfort in looking after other children. Bongeka spoke of her nephew Onke as "my only baby now" and Anne referred to her niece Mia as her "other child".

**Identity change.** The women did not easily identify change not related to motherhood. Zanele said that the experience had matured her, enabled her to deal with pain. Jean, Bongeka and Nosipho described how they had become much more aware of others' pain, and were willing to help and listen to people more than before the loss. These are themes which have been prevalent in previous studies (Cacciotore, 2010; Lichtental et al., 2010).

Two of the narratives pursued a redemptive story line which indicated a very clear change in identity. Bongeka's narrative was structured around her relationship with her abusive boyfriend. After the baby's death, she was able to break up with him and pursue a new identity as a horticulture student. She described herself as "very, very free." Anne saw her transformation as fundamental:

I wouldn't care about anyone else, as long as I had what I needed to have. That's the type of person I used to be. And the whole... my baby's death and whatever... it made me a totally different person (Anne).

**Social negotiation of identity.** Because bereavement, even that of a little-known baby, is a shared experience, talking about it is part of identity and role revision (Baddeley & Singer, 2009). For women who had strong social support, there was evidence that identity reconstruction took place within conversations and interactions with others. Some of these reinforced their roles as mothers. Ntombekhaya, Zanele, Nosandla and Nosipho had

conversations with their husbands or partners about having another baby. Older women (grandmothers, mothers and aunts) played a part in comforting, giving advice about how to cope with the loss and reassuring them that they could have another baby. They exhorted the women to “be strong” (Ayanda, Nosipho), to trust and not give up hope (Nosandla, Jean) and to think of the future (Ntombekhaya). Anne renegotiated her identity with her mother and especially with her pastor, with whom she reported having conversations about her guilt, forgiving herself, and leading a different kind of life.

Sometimes reshaping identity involves changing social circles: for example, Ayanda said she no longer socialised with her friends because they were either people she used to party and drink with, or because they had children and being with them was too painful. She and her boyfriend moved to a different area, where they hoped to start a new life and have another baby.

Gillies and Neimeyer (2006) see the reshaping of identity as one of the three tasks of meaning-making after loss. The fact that most of the women shaped their identities around continuing motherhood is unsurprising, and probably adaptive, as studies have consistently shown that a significant decrease in the intensity of grief occurs after the birth of a viable baby subsequent to the loss (Hughes, Turton & Evans, 1999; Lin & Lasker, 1996; Obi et. al, 2009; Theut et al., 1989; Zeanah & Harmon, 1995). Becoming a mother who actually has a child to mother resolves the core contradiction of the bereaved mother’s identity.

**Affirming the baby as a person to be mourned and continuing the bond.** One of the tasks which faces parents who lose babies is to establish the validity of their loss, especially when few or none in their community have seen the baby (Klas, 2001; Neimeyer, 2006). Some of them expressed the need to remember the baby, as though forgetting was another loss to be avoided.

You are not supposed to forget the death of your baby because regardless of whether the baby is alive or not, it’s a part of you and always will be. (Zanele).

I don’t want to get over the pain of losing her. Because I don’t know her, so if get I over losing her, then I forget her – because I never knew her (Zodwa).

Remembering serves two functions: it affirms the baby as a person to be mourned; and facilitates continuing bonds with the child in an attempt to integrate his or her life and death into the mother’s daily reality (Neimeyer, Baldwin, & Gillies, 2006). This takes place through using mementoes, having conversations, maintaining mental images of the baby, engaging in rituals, and believing in the continued existence of the baby in a spiritual dimension.



**Mementoes.** Photographs are important in sharing and remembering the brief life of the baby. Twelve of the women had photographs either on their cell phones, or pictures provided by the ICU at MH. Jean and Norma displayed these photographs in their homes. Norma's family also all had a picture of Noah. Ntombekhaya explained how looking at the pictures and the footprints which the hospital made, helped her: "It's like there is something I have, a piece of her for me, even though she's not there."

Baby clothes bought during the pregnancy also served as mementoes. Nontombi, Nosipho and Ayabonga spoke of holding and touching these.

I would take all the clothes and take a look at them and look and look and look. And every time I did that the tears would start to come; my heart was breaking. (Nontombi)

Nosipho's next baby, Simthandile, wore these clothes and she said,

I look at it and say, this is not yours, Simthandile. This belongs to my baby. Because I loved - I'm still going to love him.

Layne (2000) comments on how often baby clothes are mentioned in narratives of perinatal loss, pointing out the significance of clothes in marking humanness and personhood. For bereaved mothers in this study, they seemed to act as symbols of both life and death, of presence and of absence, of what was longed for and what was unrealised.

**Conversations.** Social support and interaction is critical in the task of remembering. There are few stories to tell about such brief life, so conversations seemed to revolve around talking about what the baby looked like (Jean, Nosandla, Zodwa, Nosipho), or imagining what the child would have been doing (Jean, Nosandla, Naziema) or about the death (Nosipho, Jean, Norma, Naziema, Nosandla, Ayanda).

*So nou en dan in die aande, as my Ma ook even sê, "Hy het Corbin se neus", of, "Hy het Corbin se gesig. Hoe sal dit gewees het as hy en Corbin, as hulle . . . ?"* (Now and then in the evening, my mom even says, "He has Corbin's nose", or, "He has Corbin's face. How would it be if he and Corbin, if they . . . ?") (Jean, comparing her next baby to Corbin)

It's a very sore subject to talk about - but again I find that talking about it, you will joke about it and say, he would have been doing this and he would have been doing that. (Naziema)

I speak to anyone who asks me about it. I speak a lot about Noah. (Norma)

Someone will say, "You have two babies", and I'll say, "No, I don't, I have three babies". And then that person will ask, "Where is the other one?" And then I'll say, "He's dead, but in my mind he is still with me". (Nosipho)

**Keeping the baby in mind.** These stories and reflections need an audience, but women who had little social support resorted to other ways of maintaining a sense of the baby's life. Ayabonga said she looked at other children to help her remember, and had a secret name for

her daughter: Qhama, which means sunflower. Vuyokhazi's boyfriend deleted her photograph; all she had left was a list of names she could have given to her baby, and she looked at these from time to time. Nontombi explained how she wrote about her daughter when she felt sad, which made her feel better.

Five of the women mentioned that they had clear pictures of their babies in their minds. Some of these pictures were traumatic, and illustrate the bitter sweetness of not forgetting. They are captured in evocative and painful descriptions:

My baby was very very terrible. I can't talk because there are a lot of wires. So I just touched her and changed her nappies. (Ayabonga)

She gave the baby to me. Then I put it on my chest. That is when she was breathing heavily, like huh huh huh after the crying. And then afterwards, she died. She died. (Ayanda)

The baby was very small. Even forgetting to breathe. He thinks he's still inside my womb. (Bongeka)

**Funerals and rituals.** Rituals and funerals are important communal activities which give meaning and substance to the life and death of the baby. Eight of the women had funerals for their babies, which their families organised and paid for. Five of the women were unable to afford a funeral (which is a source of distress to them), and two felt that having a grave would increase their sense of loss. Nosipho, Nosandla and Jean explained why they chose not to let the hospital dispose of the body. These explanations reveal the significance of social support in establishing the meaning of the baby as a person to be mourned.

My grandmother said, "No, we can't burn the baby because she won't recover. The grief won't go away if she burnt the baby. We have to bury the baby". (Nosipho)

Now, all of us we did agree here we are going to take the child and bury him to us in the location... because it's our blood, and you can't just take our blood and we don't even know. (Nosandla)

My grandma said, "No, this is like a person. *Is 'n mens, ons moet 'n funeral vir hom hê*". (Jean)

Norma and Naziema described other family rituals. Norma's family lit Noah's baptism candle on his first birthday. She said:

It was a quite nice. It was a nice feeling. I was happy the whole day long! My baby is a year today.

Naziema spoke of her other children's grief over the baby's death:

They know he was part of us for a short while. They would write letters and then they will take it with them and then I'll just dig a hole and put the letters in there and they will cover it up again.

**The baby as a spiritual being.** Naziema and Jean spoke of their sense of the continued presence of the baby in their lives.

Many times I hear the blocks (*of the floor in her flat*) moving. At first I was scared, but afterwards I realised that it could only be him visiting. (Naziema)

Jean said she believes that Corbin is an angel and sometimes said to her older daughter, “Corbin is watching over us tonight.” Nosipho, Nosandla, and Ntombekhaya described how they visit the grave to speak to their baby.

If I don’t feel fine and I don’t feel okay, I normally run to her. You know, I go on my knees and I ask from her, just help me now. (Ntombekhaya)

Two narratives – those of Nonkululeko and Vuyokhazi - stand out because they reveal very little sense of the ongoing presence of the baby. The child had no name, there was no funeral, and there are few descriptions of the baby. These two women were the most socially isolated; perhaps this attests to the critical importance of social support in affirming and establishing ongoing bonds with the baby who has died.

**Answering the question “why”: cause, blame and reason.** In different ways, all the women tried to make sense of the loss. This involved trying to find concrete medical reasons for the baby’s death, apportioning blame, reflecting on religious dimensions of the bereavement, and, in some instances, identifying unique personal reasons for the loss.

**Medical causes.** Ten of the women gave birth to premature babies, three babies died of infection, one swallowed meconium in utero, and one had a twisted intestine. They were able to explain with varying degrees of understanding the medical reasons that had been given to them for the death. Norma, Naziema and Zanele, who were the most informed, sought help from medical practitioners (the first two at the state hospital and Zanele with a private doctor) in trying to find the reason for the death. Ntombekhaya, who also struggled with the question of what had gone wrong, made an appointment to see the consulting paediatrician at MH after the interview to answer her questions.

The question which haunted all of them (except Nonkululeko) was why the medical problem occurred in the first place. Zodwa and Nontombi came back to this question repeatedly and unhappily in their narratives, wondering why one of their babies was affected and not the other. Nontombi had had a baby before her loss, and Zodwa had another baby after her loss. Nontombi’s first 14 narrative segments structurally reflect this confusion, veering between contradictory statements of hope and despair: “I thought something was wrong; I saw that everything was fine; The nurses think something is wrong; Maybe there is nothing wrong; I couldn’t see anything wrong; maybe something very serious is wrong”, until the uncertainty ends with the tearful certainty, “I’m not going to go back home with the baby.”

The following are three of the five occasions that Nontombi spoke about her confusion.

I was even asking even the first time, why these things didn't happen the first time, because it's not the first time I'm having a baby. Why didn't the germ do the same thing? What is wrong? Because I did give birth there first time and nothing was wrong. There was nothing about germs and infections. The baby was just fine.

I can't do anything. I don't even know what happened and what they did with the baby. I just don't know anything.

I was thinking in the first place, because I was thinking, maybe it's the bad spirit. Why didn't he come in the first place? Then, the second time he is coming. Then it was not fine.

Towards the end of the interview, she spoke resignedly about coming to accept the death: "The baby has just passed way. Nothing is going to put it back." However, for her, like Zodwa, many questions were not resolved.

There was a high level of frustration expressed at the difficulty in understanding what really happened. Zanele summed this up:

If you can't afford, you just have to accept things that happen to you without any explanation. That is how it is with the life we are living; if you are less fortunate, things happen to you and you don't even understand why they happen.

**Blame.** In the absence of adequate explanations, many of the mothers resorted to blaming themselves or others. The role of blame in adjustment following bereavement is not consistent. An external attribution is thought to buffer self-esteem and an internal attribution is likely to increase feelings of guilt and depression, although some research suggests that blaming oneself can restore a sense of being in control (Downey et al., 1990). The women in this study showed attributional complexity – blaming themselves and others, sometimes simultaneously – which has been found to be more prevalent when the death is experienced as traumatic (Weinberg, 2001). For example, Ayanda (who lost two babies) blamed herself, she blamed the medical establishment, and she blamed the ill-wishes of others. The reasons behind the blaming were not always clear, but seemed to serve particular functions for individual women.

*Blaming medical care.* Eight of them blamed the loss on poor medical care, which was discussed earlier. They blamed the death on having to wait for a long time for attention (Jean, Vuyokhazi, Zanele, Nontombi), staff not diagnosing the problem properly (Nontombi, Zodwa, Zanele) or not responding with the right treatment (Ayanda, Jean, Zanele, Nosandla). The last group all referred to stories of other women (friends or relatives) whose premature babies survived to prove that they had not had good treatment. Jean, Ayanda, and Nosandla

told of conversations they had had with friends and family about medical incompetence which gives interesting insight into how blame can be socially constructed and reinforced. Telling the story seemed to confirm to the mothers that they were justified in blaming the MOU or hospital.

I think if the doctor were present at the moment I gave birth, it would have made much difference. At least she would have known what to do at that moment, or at least put my baby under the glass. Because even if I tell my aunt the story of that day and how it went that day, she also asked me how - she doesn't understand. Because at least they could have helped. (Ayanda)

My friends who didn't know what happened, I told them everything. Even then they said that the way I was telling them the story was like the people that needed to be blamed, it's the people from that hospital. (Nosandla)

*Blaming other people.* Blaming others was a source of conflict for many of the women. Ayanda and Bongeka's boyfriends blamed them for the baby's death, resulting in bitter arguments.

Every time he was phoning and shouting at me, and telling me that I'm the one who kill the baby. (Bongeka)

Each and every time we met or were together, we would quarrel. And he would tell me that, "it's because you don't listen, that's why you've lost the baby". (Ayanda)

Vuyokhazi and Bongeka blamed their boyfriends for the loss because of the stress they experienced being in a conflictual relationship during the pregnancy.

I think I was three weeks and he beat me up until I was unable to do things for myself, like to eat. And then I think that also affected the baby because I was in my early early weeks. (Bongeka)

We always fought a lot (5) and I was always blaming, blaming, blaming him for my baby's loss. (Vuyokhazi)

Ayanda and Nontombi blamed people in their community, wondering if they had put some sort of curse on them.

We were blaming some people, and he (*her boyfriend*) was asking me to go and see that traditional healer so we can see (3) it's someone doing this. You know these African things. (Ayanda)

I thought maybe it was a bad spirit from where I was staying before, because they say why did I lose my baby. Maybe the people were jealous or anything like that. (Nontombi)

Jean blamed her mother-in-law because they fought a lot when she was pregnant; her in-laws blamed her because she gambled regularly while she was pregnant. Again, it is clear that her social group (in this case, her family) helped to construct the blame narrative:

*My familie voel sterk dis deur hulle wat ek die baba verloor het. Hulle blame tot vandag vir hulle. Because by Corbin se funeral, toe wou my een auntie vir haar toe slaan – my skoonma toe slaan. En toe sê my auntie, "Was dit nie vir jou nie, dan het*

*daai baby nog gelewe vandag*". (My family feel strongly it's because of them that I lost the baby. They blame them even to this day. Because at Corbin's funeral, one of my aunts wanted to hit her - to hit my mother-in-law. And then my aunt said, "If it wasn't for you, that baby would still be alive today".) (Jean)

The conflict generated by blaming others added an additional emotional burden to these women, in some instances (Ayanda, Vuyokhazi) alienating them from much-needed support.

**Self-blame.** Similar to findings in previous research (Cacciotore, 2010; Covington & Theut, 1993; Kavanaugh & Hershberger, 2005; Wing et al., 2001), eight of the women blamed themselves for the death. Ayanda blamed her body for not being able to keep her babies to term. She said, "I always have questions in my mind: what is wrong with me; what is wrong with my womb?" Bongeka blamed herself for working while she was pregnant; Nonkululeko blamed herself for falling pregnant in the first place; and Nontombi blamed herself without specifying why. It seemed as though these unfounded guilt responses did, as theory suggests, increase the women's feelings of helplessness. Finding a comprehensible reason for the death may be a way of relieving guilty feelings. Zanele blamed herself until she found out that the baby was born prematurely because she had an incompetent cervix. Then, she said, "I understood, ok, it wasn't really my fault."

For the three women who had clear reason to blame themselves, doing so seemed to enable them to accept what happened and make different choices. Anne (although she had no medical evidence for this) was sure that her baby died because she took drugs while pregnant. She said she will never take drugs again. Ntombekhaya did not book into a clinic when she was pregnant, and vowed she would take greater care if she fell pregnant again. Nosipho also didn't book.

I was angry with myself because I didn't go to the hospital to make sure everything is fine - if I did go to the hospital maybe they were going to see what's going on. And when I got pregnant this time, when I heard that I was pregnant, I just go to the hospital at that time. I didn't wait for another month to come. (Nosipho)

**Religious explanations.** Even for the women who had some idea of what caused their loss, the existential questions continued to be troubling. Restoring existential meaning involves either assimilating the experience into pre-existing belief, or adapting belief to understand the experience (Neimeyer et al., 2010). People typically draw from religious understanding in order to do this (Uren & Wastell, 2002; Wortman & Parks, 2008). Pastors, church communities and older relatives were highly influential in encouraging the women to understand their loss in spiritual terms. Ntombekhaya and Nosipho detailed conversations with their grandmothers, Ayanda with her aunt, Nosandla with her mother, Anne with her

pastor, Norma with her family, and Naziema with her father. Mostly, understanding meant accepting that God is all-powerful and all-knowing.

It was only God's will. You know, God knows why that happened. (Ntombekhaya)

God knows why he took my baby. (Nosipho)

Those are God's plans. Before that baby was even conceived, God had plans for him already. (Naziema)

To us, God has a different purpose for Noah. Somewhere else he is free. (Norma)

The main function of this belief seemed to be to help them view the world as a safe place where it is possible to hope, as God is in control. However, it did not always accord with meanings or explanations the women raised elsewhere. For example, Nosandla (whose narrative contains by far the most religious references) blamed the MOU for the baby's death, yet said that God was responsible for what happened. She claimed that "if you have faith in God, you'll have another child", but on the other hand said that "my husband is planning to have another child." Jean said she has "made peace" with Corbin's death, yet her narrative was full of restless accusation against those she held responsible for his death.

Nonkululeko's faith in God appeared to be at odds with her anger and distress over her multiple losses. Reasoning her way through this seemed to help her to reach a point of acceptance. This could, however, be more an indicator of her own lack of power in the face of her situation than belief in God's control.

If you are supposed to get a baby, you are supposed to get it, but if you are not supposed to, only God knows why. Yes, I said that to my baby when she passed away. But it's the only thing that left to me. When I think that I lost my job at the same times and my girl is supposed to be in school, she is not in school yet. But even that, I accept it.

Zanele was ambivalent about the role of God in the trauma. She was still trying to accommodate her beliefs so that they fitted in with her experience.

It distanced me to God. Because you are angry: why did he let that happen? The next minute you are crying to him for comfort.

The fact that she had more control over her life than some of the other women (at the time of the interview, she was working as a junior financial analyst, and had medical aid to use private health care for her subsequent babies) could be why she was able to articulate and live with this ambivalence. There was less urgent need for someone/ something else to be in control.

Some of the women resolved their ambivalence through personal explanations of why God allowed their baby to die. Ayabonga and Bongeka believed that their lives would have been more difficult had the baby lived. Norma and Naziema believed that their babies would

have suffered through disability if they had survived. Nosipho thought that her baby had died because her boyfriend had lost his job and they would not have been able to afford to look after the child.

The women's religious explanations seemed to enable them to assimilate their loss into pre-existing belief systems. These hold that God is in control and all-powerful, and that the deaths are not random events. This raises the question of whether the women's diminished power over their own lives draws them to a religious framework which reinforces their lack of control and enables them to accept rather than rail against the multiple losses and difficulties of their lives. Meaning-making which resolves in simply accepting tragedy may be an adaptive way of dealing with loss in their context.

### **Reflections on the search for meaning.**

*Was meaning found?* All of the women's narratives contained at least two of the above elements of meaning-making (affirming the baby as a person to be mourned and continuing the bond, re-working identity, looking for concrete and existential reasons for the death). However, the extent to which these had been developed and resolved varied considerably.

*"At peace"*. Seven of them seemed to have come to an understanding of the loss which helped them to feel at peace and get on with their lives. This was evident in the relative coherence of their narratives, and explanatory statements which they made. Norma, Nosandla and Naziema's understandings were based on religious conviction which their families shared. Norma said toward the end of her interview, "There's no anger, just accept it. I feel sad, yes. I feel sad, but we're coping." Her husband (who had sat in on the interview at her request, but did not actively participate) added, "I think basically we've said it all. We are at peace."

Bongeka and Anne (as discussed above) reached a measure of resolution through understanding how the baby's death had transformed their lives. Zanele and Nosipho found meaning in motherhood, as having babies subsequent to their loss seemed to have helped them accept what had happened.

*Looking to the future*. Three of the women seemed still to be questioning, but were hopeful about their futures. Essentially, their meanings were based on what they hoped would happen. Ayabonga hoped to find work and establish a life for herself; Ayanda hoped that her third pregnancy would give her the baby she longed for, and Ntombekhaya was planning to fall pregnant. Their meanings were dependent on a reality not yet present: it was not clear how they would cope if their dreams and plans were not realised.



*“There is no answer”*. Five of the women told stories which were not always easy to follow, were repetitive or circular, and had little resolution. Jean’s was the most coherent of these, but she talked often about the conflict with her in-laws, her difficult marriage, and how these had affected her pregnancy. There were two other “blame” narratives. As mentioned earlier, Nontombi’s story was dominated by her blaming the MOU for her baby’s death. Zodwa similarly blamed medical staff both for the death and for her ignorance about what really happened. Although they included discussion around blame, Vuyokhazi and Nonkululeko’s narratives were primarily constructed around the difficulties of their circumstances, and actually mentioned their babies very little. Vuyokhazi and Zodwa both said that there was “no answer” to why their babies had died.

***How was meaning found?*** There are no obvious patterns to suggest why some women found meaning and others did not. The time since loss (which other studies have found to affect meaning-making (Gillies & Neimeyer, 2006; Holland et al., 2006) does not appear to be consistently correlated with finding meaning, although this sample is too small to be a reliable measure in this regard. Clearly Vuyokhazi and Nonkululeko’s social and financial circumstances affected their meaning-making, but Bongeka and Ayanda were in similar situations and did find some meaning. Conversely, Zodwa, whose circumstances were fairly supportive and stable, seemed unable to make sense of her loss. Thus the women’s contexts did not necessarily have a direct impact on how they made meaning, although they inevitably influenced both their experience and their understanding of the baby’s death. The narratives hint at a more complex reality, which will be discussed in the following section.

### **Context, Personal Agency and Social Support**

While all the women (with the possible exception of Norma) perceived their contexts as difficult, the effect this had on meaning-making was mediated by their sense of personal agency and social support. These two factors facilitated the process of meaning-making, and informed the meanings which were reached.

**Agency.** According to social cognitive theory, agents are “self-organising, pro-active, self-regulating and self-reflecting”. This enables them to “transcend the dictates of the immediate environment and... shape their life circumstances and the course their life takes” (Bandura, 2006, p. 164). Central to this is belief in personal efficacy. Within the narratives, the women portrayed themselves as agentic or not by statements of self-definition and using a number of linguistic and structural devices. Diminished agency was evident in passive constructions, nominalisation of emotions, generic self-reference, hypothetical past structures and verbs of necessity. Agency was conveyed by the opposite structures, in particular, the

consistent placing of “I” as the active subject of sentences (Bauer & Bonnano, 2001; Capps & Bonnano, 2000).

In all the narratives, the narrators shifted between expressions of diminished agency and expressions of stronger agency, although one pattern did tend to dominate. This might have been an indication that they were in the process of renegotiating their identity as part of the meaning-making after the bereavement. Often diminished agency was expressed in relation to past events (e.g. the birth and death of the baby), whereas descriptions of more recent events suggest greater personal agency. In general, the narratives of agency included more reflective passages than those where there was consistently evidence of diminished agency, and the bereaved mothers spoke readily about identity change and future goals.

Women who appeared agentic were active in monitoring their own grieving process, choosing to draw on social support when it was helpful, and rejecting it when it was not. This at times meant acting against social norms or questioning widely accepted social explanation of events.

**Social support.** Social support can be understood to be “emotional, economic and practical help or information provided to the affected individual by significant others” (Dyregrov, 2003, p.24). In this study, multiple levels of social support were evident, including partners, immediate and extended families, friendship circles and social institutions (church, school, clinic, hospital). Social support was given through financial assistance, talking about the loss, and engaging in communal rituals. The centrality of social support was highlighted by the inclusion of other characters in many narrative segments, extensive use of reported speech, frequent use of collective pronouns (e.g. “our baby” rather than “my baby”), and statements about the significance of support. In keeping with previous research, the most important social support came from immediate family (Abboud & Liamputtong, 2005; Cacciotore et al., 2009, Wing et al., 2001). A finding in this study which has not been explored in previous studies is the particularly critical role of older women (mothers, aunts, grandmothers) in meaning-making.

**Four kinds of narratives.** Predicated on these interacting factors, four different kinds of narratives were evident. These reflected the ways in which bereaved mothers situated themselves in relation to their contexts. This positioning seemed to have more influence on meanings and meaning-making strategies than the effect of their context.

In the first kind of narrative, the narrator portrayed herself as overwhelmed by circumstances (Vuyokhazi, Nontombi, and Nonkululeko). She had little sense of personal agency and not much social support. The death of the baby made little sense, and the future

seemed hopeless or agonisingly difficult. Others were blamed for the death, and she was seen as a victim of circumstances or malevolence. The narratives revealed high levels of distress.

In the second kind of narrative, the narrator depicted herself as someone who was capable of overcoming circumstances because of her personal strength (Ayabonga and Bongeka). She had little social support, but was able to take the initiative in accessing help. In these narratives, the meaning of the baby's death was related primarily to personal factors.

In the third kind of narrative, the narrator described strong social support networks. For Norma, Nosandla and Naziema, the central meanings of the baby's death were related to issues in the parental dyad, or in the broader family. Religious beliefs, shared by their families, played a very important role in maintaining a continuity of meaning. The strength of the support seemed to somewhat diminish their agency, but they derived security and comfort from conforming to the norms of their support structure.

In the fourth kind of narrative, the narrator had a great deal of social support, but also a well-developed sense of personal agency, and she was able to make her own decisions and interpretations (Jean, Zanele, Anne, Ayanda, Nosipho, Ntombekhaya).

The remainder of this section will examine an example of each kind of narrative in some detail, and will conclude with a discussion of Zodwa's narrative, which does not easily fit any of these patterns.

***Overwhelmed and alone: Vuyokhazi.*** Vuyokhazi had broken up with her boyfriend two months before the interview took place. This essentially defined the way she told her story. Recounting the death of the baby took only the first five of the 33 narrative segments. After this, with a great deal of prompting by the interviewer, she told of her attempts to return to normal life and go back to college. At the end of the 23<sup>rd</sup> narrative segment, when the interviewer leaned forward to turn off the recorder, a significant shift happened: she said (tearfully, but with remarkable clarity), "I am not finished, not finished". She then went on to tell fluently and passionately (in what is perhaps the only fully developed story in the interview) of breaking up with her boyfriend because she found that he had gone to another girlfriend and his son in the Eastern Cape. The placing of this story indicates its central importance. In losing him, she lost her accommodation, financial security and emotional support. The story of her baby's death found little space in this context of overwhelming loss: it was ragged and difficult, full of long silences and painful feelings expressed in tears and physical agitation rather than words. Her inability to describe or explain what happened can be understood in the light of her current loss, her lack of support, and her diminished sense of personal agency.

This diminished sense of agency was reflected in her language, which was punctuated with repeated phrases like “I don’t know”, “I don’t remember”, “I can’t think”, which create an obscurity around not only the death of the baby, but Vuyokhazi herself. She mostly portrayed herself as passive.

In her opening narrative, in which she recounted going to the MOU in early labour, she appeared to be simply following orders.

They said I must wait outside, because the the the nurse were busy with some other persons I waited in line. Then they said I must get inside (5) Ja (4) They checked me. They didn’t tell me much. They took me (5) I think it was 9 o’clock in the morning the following day. They took me to here.

This vignette also depicts the busyness and impersonal treatment she received at the clinic. She often referred to the nurses as “they” which emphasised her perception of their disengagement, and her lack of control in the situation.

Her social support system was depicted as unstable and fragmented. Having moved to Cape Town from the Eastern Cape to complete her schooling, she had no immediate family close to her, and no fixed home. She moved from staying with one aunt to another, then with cousins, and then with her boyfriend. A kind of spatial dislocation pervaded her narrative: she went into labour while staying in A, but should have been in B, where her clinic booking was, and ended up at MH. She returned to college four days after her baby’s death. This was complicated by the fact that all her books were at her boyfriend’s house, but she had gone to stay with her cousins again. She had to leave college because she could not afford the fees. Her dire financial situation affected her dislocation. She was totally dependent on others for accommodation and support, as the R400 a month her mother sent to her was not enough for her basic needs. The disintegration of her social support system was in part due to her economic difficulties, which were located in broader contextual and structural problems such as high unemployment and poor school facilities in South African rural areas. Complex social norms around her unplanned pregnancy meant that she was afraid to tell her parents about her situation, and that many people were unaware of her pregnancy. When asked about what ritual usually happens in her community when a baby dies, she said, “I didn’t have a big stomach. Some of the people they didn’t know that I am pregnant.”

She was not entirely without help. When asked how her cousin had supported her after the baby’s death, she said, “She was taking care of me, because he always put a bucket of water so that I can wash.” This seemingly small gesture was important to her; however, in comparison to what other women described of their social support (others spending a lot of

time with them, giving them meals, helping with hospital and funeral arrangements), it highlights her isolation.

How did this affect the way she makes meaning of her loss? Firstly, there was little opportunity to establish a sense of the baby as a person to be mourned by talking about her to others. Secondly, no conversations about the cause of the death took place outside of the parent dyad, where it became a source of conflict between them. Thirdly, in other narratives, social support seemed to help generate hope, but Vuyokhazi's narrative concluded with an ongoing sense of despair.

Families help to negotiate meaning by remembering and speaking about the person who has died (Nadeau, 2001). This is particularly important in perinatal loss where so few memories are available, and grieving is helped by finding ways of establishing the baby as a real person to mourn. In Vuyokhazi's situation, no one saw the baby apart from her and she had little opportunity for conversation about what happened. She reported two such conversations, with her cousin and, later, her boyfriend's mother. They were able to validate her grief as they had also lost babies, and they told her to try to have another baby.

In the absence of a stronger family base, her partner took on a central role as co-creator of meaning. There is some evidence that they did try to make sense of what happened. He cried with her over the death, and they tried to fall pregnant again. But their relationship even before the death was fraught with conflict, sometimes with physical violence. Following the death, she blamed him repeatedly for what had happened. Blaming could have been part of her attempt to increase her own sense of efficacy (Downey et al., 1990), but this kind of vengeful blame has often been found to lead to poorer outcomes (Weinberg, 2001). In Vuyokhazi's case, it resulted in the erosion of an already fragile support system and locked her into irresolvable rumination. Of the eight reported interactions with her boyfriend, three referred to her blaming him, and one to him deleting the baby's photograph on her cell phone. (The others refer to his ambivalence about the pregnancy, tearfulness after the death, his telling her she demands too much, and her telling him about coming to the interview). When she broke up with him, her final words before she turned off her cell phone were, "Yho, you are happy but you are not happy because you are the one who killed my child."

For Vuyokhazi, the meaning of the baby's death was inextricably bound with the loss of her boyfriend. There was little space for grieving for her daughter in the context of multiple losses; she was unable to make sense of or find benefit in the death. Bereaved people who cannot find meaning in the death of a loved one frequently experience prolonged and intense

grief. This can be exacerbated by patterns of rumination which increase distress rather than facilitate understanding as they disrupt narrative construction (Michael & Snyder, 2005; Nolen-Hoeksema, Wiseo, & Lynbormirsky, 2006). Talking about the distress rather than thinking constantly is one of the ways to break this pattern. Where no conversation partners are available, it can be very difficult to move beyond this (Baddeley & Singer, 2009). Vuyokhazi's narrative indicated patterns of rumination concomitant with inability to find meaning. This was encapsulated in the following interchange:

I: Do you ever wonder why your baby died?

V: Ja, all the time

I: And what do you think?

V: There is no answer.

Vuyokhazi's narrative showed the most profoundly diminished agency and least social support of all the narratives. This may be partly accounted for by the relatively short length of time between her loss and the interview (14 months;  $M = 22$  months) and her recent break-up with her boyfriend. Her contextual positioning affected her ability to make meaning of her loss as she was unable to establish a sense of her baby as a person to be mourned, unable to come to an understanding of why her baby died, and unable to move out of the unhelpful patterns of rumination. Her inability to create a coherent narrative of the baby's death reflects her difficulty in organising the experience into a meaningful framework (Michael & Snyder, 2005). Towards the end of the interview, she was asked what she thought about the future. Her response was, "My future? Whew!" followed by a deep sigh and a long silence. The combination of economic and relational difficulties, affecting and affected by the death of her baby, and the constraints these put on her ability to make meaning of the death, seem to have resulted in an incapacitating grief.

***"No one can help me; I'm going to be strong": Ayabonga.*** Ayabonga's narrative created a strong impression of herself as a strong, lone figure in a harsh and unsupportive environment. This portrayal was so skilfully wrought that expressions of her vulnerability or instances of support from others came almost as a surprise. The first 15 narrative segments unfolded as a litany of distress at what she repeatedly referred to as "my situation": her mother was dead; her father had seven other children so couldn't help her; she lived with six other adults in a "backyard" dwelling; her aunt, with whom she used to live, beat her and made her clean the house even when she was advanced in her pregnancy; her boyfriend threatened to take her to the police when she wanted to terminate the unplanned pregnancy, and later abandoned her when she was eight months pregnant; the clinic didn't help her in her protracted labour; she dropped out of school after the baby died because of the "hardness";

then she tried to earn money as a domestic worker but was only paid R100 for a weekend's labour. The little help she did receive was overshadowed by her difficulties. She concluded, "So I didn't have a good life anywhere." At the time of the interview, Ayabonga had just turned 20.

Parallel to these stories was a description of herself as someone who takes action against hardship. Her resilience was highlighted in juxtaposition to her environment. Throughout the narrative, she used a particular sentence structure where she described the difficulty, and then presented her response. There are many of these, for example:

No one is supporting me now; I have to go and look for a job

They are beating me, and now I have a dent here, nê, so I decided to move because I need peace

I know that there is no one who can care for me and the baby, so I decided to do an abortion.

After that (*deciding not to have an abortion*) I just told my body, my heart and my brain that no, I can accept this and it's mine.

Ayabonga often described herself as being alone. This was not framed negatively, but as part of the personal discourse of herself as strong and independent.

I know that I am strong and I'm going to be strong... because if I was weak, I won't survive. And even if I'm not talking with other people, no one can help me. So I'm proud of me, and I know that I'm going to be strong for a long time. And I will help other womens that have this problem that I have.

She portrayed herself as taking charge of her own recovery and making decisions about how to respond to challenges. She was, however, not reticent to ask for help, and told of borrowing money from people in the community. Her narrative undoubtedly underplayed her need for help. Near the beginning of the interview, a short sentence which ran contrary to her main theme slipped in: "I still need more support". And her final comment to the interviewer was similarly telling:

If you have something that can help me, you can help. I just want someone who can help me so that I can survive.

An earlier narrative segment, when she explained how she borrowed money to come to the interview because "maybe it's important", hinted that she had expectations of getting help of some kind. Apart from the ethical questions this raises, it also illuminates why she told her story in the way she did, although this was probably an unconscious strategy. Highlighting her contextual difficulties served to elicit sympathy, while focusing on her strength engendered admiration. Research suggests that this kind of strategy is more likely to evoke support from listeners, who become weary and dismissive of narrators' accounts of

personal struggle and helplessness (Baddeley & Singer, 2009; Nolen-Hoeksema et al., 2006). Ayabonga's central meaning – she is strong, life is hard – is thus functional in helping her to attain her goal of social support. The narrative construction is of itself an expression of her agency.

How did her isolation and strong sense of personal agency affect the way she makes sense of her baby's death? Her meanings largely focussed on her identity. She regarded having had a baby an achievement.

I had a baby and I am proud of it, but she was dying. So I'm proud of myself.

Initially, she decided to have an abortion because she knew that no one would help her to look after a baby. However, once she had decided not to have an abortion, she regarded having the child as a way of alleviating her aloneness.

A: I was feeling that my baby was going to be okay because I needed her.

I: You felt you needed her?

A: Ja.

I: Why? Can you explain that to me? Why do you think you needed her?

A: I need her, because this is my baby and it's there for me. That's why I felt like I need her, because it's mine and I cared for her for nine months full. So it's my baby. That's why.

After the baby died, she reverted to her initial feeling about the pregnancy. She explained that maybe God helped her by taking her child because of the difficulties of her life.

Because it's difficult now, but I don't have a baby. If I had a baby, I think it was more difficult.

Her grief was described with almost no reference to anyone else: there was no funeral, no one else wept. Her aunt quickly passed the baby clothes on to another cousin who was pregnant. Socially, the death was almost a non-event. She had no one to discuss the baby with, and told how she holds onto a mental picture of her ("even the way she slept in this small bed") as a means of continuing the baby's presence in her life. Ironically, the fact that she had had a baby meant that people no longer regarded her as a child and were less willing to give her money.

Ayabonga's story illustrates some of the difficulties of meaning-making in isolation. Possibly because she had little opportunity to make sense of the baby's death with others, her meanings remained somewhat contradictory: she is a child who has had a child and so is no longer a child; she wanted an abortion but is proud of having had a baby; she is distressed by the death, but knows that not having a baby makes her life easier; if the clinic had been better, the baby would still be alive – but it was God's will that the baby die; she is a strong women who needs no help but won't survive without it. Although there are often paradoxes inherent



in meanings, repeated tellings over time can help to integrate contradictory perspectives (Baddeley & Singer, 2009). It seems as if the interview, in addition to being help-seeking behaviour, also served as a venue for her to construct and reflect on a bereavement narrative which is not often told.

***“Everyone they were there for me”:*** *Nosandla*. Nosandla gave an account of her baby’s birth and death story in vivid and evocative detail, from her opening statement, “When I was pregnant, I was feeling happy” to the end of the 20<sup>th</sup> narrative segment, “We buried him in (*name of township*)”. She required no prompting, and it seemed as if this was a story she had told many times before. During the course of the interview, it became obvious that it *was* a well-practiced narrative: she recounted telling it to her brother-in-law, her friends, and her work colleagues. In addition she, her mother and her husband often discussed what had happened. She explained:

This thing is not a thing that you can keep it inside you. I used to keep things, but this one, I didn’t keep quiet for it. If I talk it out now, I’ll be fine.

Because she had a very supportive social circle, there was plenty of opportunity for her to “talk it out”. However, the narrative was full of voices which seem to drown out her own, in particular her husband’s and her mother’s. The dominant religious discourse by which Nosandla made sense of her loss, was expressed and reinforced by these two prominent characters, as well as by her friends, other family members, and television programmes she reported watching.

When she was six months pregnant, Nosandla went to spend some time with her mother in the township, because she was lonely (an indication of how much she needed social support). While she was there, she went into premature labour, and her mother had to get her to the MOU in the middle of the night. When they arrived, she was told she was not allowed to deliver there because she had booked into MH, and needed to wait for an ambulance to transfer her. Her description of this was harrowing, and she came back to it four more times in her narrative in similar ways:

I can feel the head of the baby is out and the pain is more... too much. And the blood keeps on running. They say I must fold my legs and keep on breathing, breathing, breathing. I say, I can’t breathe. As I’m talking to you right now, I feel the head is out already. They say don’t push that baby, don’t push that baby.

The baby was born as soon as she arrived at MH. Nosandla said three times, “the baby came out by itself (himself)”, as though she had little role in the delivery. Her language does not reveal diminished agency to a marked degree, but her stories show her to be very dependent on the advice and support of others, and quite compliant. Five times she phoned

her husband for help, referred six times to her mother's advice, and told of listening to advice from her work colleagues and friends.

Although Nosandla told of all the practical help her mother gave her, her role was predominantly that of a comforter and adviser. She "kept on praying, praying, praying" for the baby, reassuring her daughter that the baby would survive, but if he didn't, God would give her another one. She told the staff at MH that she would counsel Nosandla. This is a short extract from a long, repetitive narrative segment explaining what she advised:

My mother is starting to talk that I must keep trust in God. He knows the reason why he took this child... what I have to pray for, I have to pray to God that he must remove that part of thinking about that child.

Nosandla tried to follow this. The narrative segment ends with her saying:

That is why I have been asking God to remove the thought of thinking about my child. But I can't do otherwise: I *do* think about my child. Like the whole month I have been thinking about my child.

This is less an active resistance of what she is being told to do than an instinctive personal response to the loss – one which all the other bereaved mothers also experienced. However, Nosandla did not seem to allow herself room for personal and private grief. Despite her inability to follow her mother's advice, she clearly believed it to be valuable, as she later said that she would advise another woman who had lost a baby in the same way. She did not admit again to thinking about her child, and her final sentence seemed intended to reinforce her mother's wisdom, her adherence to the advice, and her recovery as a result of it.

I'm feeling fine because of the words my mother gave me – for both of us, me and my husband because those words made me stronger.

Nosandla's husband (whom she never names, but constantly refers to as "my husband", possibly as an indication of their close bond) was an active player in 20 of 39 narrative segments. Her opening statements conveyed how important he is:

When I was pregnant, I was feeling happy, because my husband and I were staying together. Even he was excited that we were going to have a second child.

The meaning of the pregnancy was inextricably bound with their relationship; she was happy, not primarily because of the pregnancy, but because she was pregnant *and* they were together. She portrayed her husband as very invested in the pregnancy: he is "excited and happy" (repeated three times in the first 25 lines); he started buying clothes early on; was very protective of her and didn't want her to walk about on her own when she was pregnant. Her own investment in the pregnancy and her pain at the loss of the baby are overshadowed by these descriptions. The first time she cried during the interview was when she described her husband's tears. She described how she and her mother had to comfort him in the hospital.

My husband was screaming, shouting, crying, all those stuffs. Now we had to comfort him that time he was crying.

Nosandla also portrayed him as very loving towards her. For example, he took her away from the hospital sooner than the medical staff wanted, because she could not cope with the crying of other babies. He then had to go to the pharmacy to get her tablets to dry her milk, because they had left the hospital too soon for these to be prescribed. The following extract captures her appreciation of him, his care of her, and his strong faith.

He didn't even go to work for a whole week. The two of us were sitting quietly, thinking of all that stuff, keep on praying. Because even him, he is a Christian who goes to church. He has been there for me throughout.

She went on to talk about how she wanted to go back to work, but he wanted her to wait for longer, and she complied. (Note how she used direct speech in describing this conversation. She did this in reporting conversations with both him and her mother, which strengthens their dynamic presence in the narrative):

I told him I'm alright now, and I'm going to look for a job. He was saying, "No, you are not yet alright, just keep on staying at home even if it's six months, until you are a hundred percent okay".

The most striking example of where she depicted herself as deferring to him was in a discussion about falling pregnant again. She repeated this again towards the end of the interview, using similar phraseology:

N: Now I'm fine because my husband is planning another one. He says he wants to replace that child because he is not happy. Even him, he keeps thinking about that child, because men can't keep on talking, but I can see that he is still thinking about the child also.

I: So are you trying to fall pregnant now? Do you also want another baby?

N: Yes, because that is what he wants.

There was an echo in this of her opening statement about being pleased to be pregnant because the two of them were together. She didn't ever speak about her own desire for a child. The gender stereotypes in this extract are marked: "men can't keep on talking"; and "yes, because that is what he wants". Given that they locate themselves within a conservative Christian paradigm, it is likely that these are at least to some extent reinforced by the traditional notion of women "submitting" to their husband, who are strong, protective and loving towards them. However, she did not express unhappiness or dissatisfaction with this, and her way of dealing with her grief is formed by this dependent/ nurturing dyad.

How did Nosandla's strong social support and muted agency affect her meaning-making? Firstly, it gave her a sense of continuity in her identity and role as a mother and wife. She said that she is "still that Nosandla that people know... I'm not like a person who

has lost a baby.” Because she was in a stable and supportive marriage, she could anticipate having another baby. The pregnancy was an extension of her relationship with her husband, the death drew them closer together, and being able to plan another baby helped her to feel “fine”.

Secondly, speaking about her experience at the MOU helped to socially reinforce blame for the death. She did not even give any consideration to the fact that she delayed going for help for 17 hours after she first felt pain. A very quiet allusion to some sense of guilt entered the narrative without being developed:

The child was suffocating there because he couldn’t breathe and he was halfway. You see, now the neck, I’m blocking him...

It is possible that her dominant pattern of reliance on others made it difficult for her to take any responsibility for what happened.

Thirdly, the grief of her family and the big funeral service helped to establish the sense of the baby as a person to be mourned. What is lacking, however, is a strong sense of a continuing bond with the child. He had no name, her mother took away the photos and told her to stop thinking about him, and her husband wanted to “replace” him. She spoke once about thinking about him, once about how he looked like Chidima, and once about imagining how he would have played. However, these were private and isolated reflections, almost contrary to the norms of her support system.

Lastly, religious themes dominate. These formed the basis of Nosandla’s personal reflections and conversations with medical staff, her mother, and her husband. There is a sequence in the narrative which moves from saying: “If he survives, it’s God” to “God gives and God takes” to “God knows the reason why” to “Put my hope in God” to “he is going to give me another child”. This belief in God’s control does not co-exist logically with blaming the MOU for the child’s death, or her husband’s plans to have another child. However, being able to accommodate, but not recognise, the contradictory views may be driven by the need to achieve univocality which provides a certain and comforting explanation for the traumatic loss.

***“I’m a strong person ... I ask for help”:* Ntombekhaya.** After my opening remarks, Ntombekhaya introduced herself and plunged straight into the story of her baby’s death. She spoke fluently, confidently and with purpose: so much so that some of the intended questions about her living conditions were never addressed.

I: I want to start by just asking you a few questions about yourself and your life, and then after that I’ll go onto asking you about what happened with your baby.

N: First of all, my name is Ntombekhaya. I grew up in the location. I stayed with my grandmother till this age.

This opening segment is significant in understanding the way she portrayed herself. She has a clear sense of who she is: “My name is Ntombekhaya”. Her explicit self-definitions included statements like “I’m a strong person”; “I’m more of a career-oriented person.” The way she spoke about her baby reinforced this strong sense of self as she referred to her as “my baby” (and not “the baby” as many of the other mothers do) and placed herself as the subject in reference to the death, saying, I lost her” and not “she died”. She portrayed herself as active and mostly in control. Out of 45 narrative segments, only three ended without a positive statement or conclusion. These are nested among ones in which there is pain, but always resolution of some sort. In one of these, she described being in hospital for five or six days after her baby died. She concluded: “It was very bad. They were holding their babies. It was very bad.” Even in this, she did not refer directly to her own feelings, but to the external situation. Elsewhere, she downplayed painful situations. Regarding her unplanned pregnancy, she said: “It was a bit tough”, and of the baby’s death she said, “It was a bit disappointing.” Although she described her grief, not once did she depict herself as a passive victim. Her actions thickened the depiction of herself as strong and in control: she broke up with her boyfriend because she was angry that he had made her pregnant; and she went back to work as soon as she could. She accepted some blame for the death because she booked into the clinic so late. Some research (Downey et al., 1990) has suggested that self-blame can be used as a strategy of re-establishing control over a situation. It is not clear if Ntombekhaya’s strong sense of agency enables her to accept blame, or if accepting blame helps her consolidate it, or if both factors are indeed important.

Ntombekhaya’s second opening statement: “I grew up in the location”, encapsulated another aspect of her narrative perspective. Her environment was depicted as stable and familiar. Her school, church, and friendship circle were all in the “location” where she grew up. This is in stark contrast to Vuyokhazi’s situation. Ntombekhaya perceived herself as being very supported by her friends, her work colleagues, the staff at MH, and especially her grandmother, who was also introduced in her opening sentence. Her grandmother raised her, supported her financially when she wasn’t working during her pregnancy, was the first to recognise that she was pregnant, and encouraged her to go to the clinic. Her position as the only child in the house with her grandmother and uncle gave her privileges which she acknowledged: “I grew up at home knowing that everything belongs to me at home”. Of her

grandmother, she said: “She’s my soul... she raise me well... she gave it all to me, her last cent, she spent it on me.”

In her narrative, Ntombekhaya’s poverty was backgrounded by the support she had from her grandmother (a domestic worker) and uncle, her own sense of agency, and her belief that she was going to get ahead. The death of her baby occupied considerably less narrative space than discussing her future desires (to have another baby and get a good job) and responses to the two reflective interview questions (“what would you say to another woman who lost a baby?” and “would having more money have made any difference?”) The latter were answered in long philosophical monologues which elaborated on her fundamental beliefs that support is crucial and accessible, and that problems can be overcome. The essence of her first answer was:

Find support from people, clinic, nurses, doctors and all that. Don’t be shy, Don’t be scared, speak it out.

And her second:

No one can live without money. You don’t have a job and the only hope you have, you must have this baby, and now you have lost this baby. Ask for help. There are people out there, there are places out there... so having those problems of not having money or being jobless, and you have lost a baby, it doesn’t mean the end of the world.

Her narrative moves swiftly forward chronologically reflecting her striving to leave the death of her baby and reconstruct her life. She spoke of the importance of the future:

You are moving forward. You are going forward and not backwards, because if you always look backwards, then you are going nowhere.

How did Ntombekhaya’s sense of agency and her strong social support affect her meaning-making? The life and death of her baby were linked to her personal and social identity. She spoke of missing her baby, saying that even though “it was like one day or two, there is that connection between the mother and the child”. She wants another baby because “I miss that part of knowing that you’ve got a child”. The death caused her to revise her goal of being just a career woman, to being a mother as well.

The enormity of the baby’s death and her strong desire to be a mother (even though the first pregnancy was unplanned) can be understood in the context of a very supportive family environment where children are valued. Their value supersedes the difficulties that come with an unplanned pregnancy, such as job loss and financial strain.

You know, if you bring a child, no matter what mistake you’ve made, no matter how hard it will be, but there’s a child now you have to let go of everything and just focus on the baby. Because God gave you a child and the child is a gift from God... I come from a family where they are very supportive. They love me, I don’t want to lie. And

if you bring a child to them it's like wow. You know, you are extending the family now.

For a woman who construes herself as strong and successful, the loss of a baby is both a personal and a social failure. Ntombekhaya's narrative gives evidence of a great deal of reflection on what has happened, and a decision to move forward. She reported talking about the baby's death with the father, her friends, counsellors and her grandmother. From these various conversations, which revolved primarily around blame, she came to the seemingly contradictory conclusions that she made a mistake and can learn from mistakes next time, and that "it was only God's will, you know God knows why that happened." Blaming herself for the baby's death enabled her to take control of what happened and direct her future differently so that she could move beyond the failure.

***"I can't seem to find my way forward": Zodwa.*** Zodwa came across as strong, almost strident, in her bearing and she spoke with very little interruption or prompting. However, despite her confident manner, a close investigation of her narrative showed a significantly diminished sense of agency, manifest in her fatalistic attitude, her confusion around the cause of her baby's death, her inability to explain her emotions, and her all-consuming anxiety over Mehluli (her next child). This is evident in the content of her story and the way she uses language.

She began very factually, recounting specific dates and detailed conversations using very few affective words. Her tone shifted slightly to one of fatalistic resignation when she described how the nurse came in the morning after delivery:

I think she saw something and she grabbed the child and she ran. By the time she was running, I felt, ag, that child is not coming back.

The opening narrative segments set the pattern of her story: she alternated between factual, almost detached story-telling to highly evocative and descriptive reflections; she changed from calling the baby "that child" to "the child" and "my baby"; she had similarly fatalistic comments throughout the narrative about other incidents (her previous infertility, her twin sister's death from AIDS, the dangers of living in the township). During the course of the narrative, she said "I don't know" 22 times. This culminated in statements such as: "I can't seem to find my way forward", and "something is missing somewhere, but I don't know what." Of her 42 narrative segments, 10 focussed on Mehluli, the baby she has had since her loss. She came back to him again and again in a circular fashion. These narrative segments were mostly ruminations about her extreme anxiety about him. She said, "The constant fear that something is going to happen to him, it's killing me". Her closing statement in the

interview is, “I don’t think I’ll fall pregnant again. I don’t think so. Constant worrying is... yho!”

The only emotion she admitted to feeling was this fear. She struggled to articulate or own other feelings around her daughter’s death. Her description of the interview with the social worker in hospital reveals her emotional blunting and confusion:

She asked me if I wanted to say something and how do I feel. But at that time I couldn’t say anything. Because I didn’t even cry at that time. Because since now I haven’t cried about that child. I don’t know why. I can’t. How can I say? You know, the feeling as if something could have been done but wasn’t done? That’s the feeling. I don’t know whether to classify it as anger or being hurt or what. I don’t know. Don’t know.

Later on, she reflected on her disappointment at how the hospital had dealt with her. Although her English was very fluent, and she told the story of baby’s death with compelling detail, in the extract below she again struggled to articulate her feelings. She used generic self-reference (“you” instead of “I”) here and elsewhere in the narrative, which is often an indication of diminished agency (Bauer & Bonnano, 2001).

You know, I don’t know whether people take it lightly or what, but losing a child is a very big deal. I don’t know whether, since they think you don’t know the child and you didn’t see the child - not knowing the child. I don’t know, but the - I’m not saying you’d want special treatment, but at least - I can’t say consideration or - maybe they should at least take into account that this is all new. It’s your first. And your file is there – it’s your first baby – obviously there’s going to be a lot of emotions attached to the losing of the child.

Despite being able to acknowledge how painful it was to lose a baby, she did not connect this directly with herself.

At first glance, Zodwa seemed to be in a far better position to engage with meaning-making than some of the other women: she was better educated; had a stable home with her mother (a teacher); was in a long-term relationship with a man whom she portrayed as loving and supportive, and had an extensive circle of friends. However, she seemed unable to draw from the support they offered. This may be because what they offered was not what she needed or because she did not communicate her need to them (Dyregrov, 2003). Her friends expected her to party as she used to:

I felt so lost. They were all rushing and preparing to go to a party and stuff, and I thought, I don’t belong here. So I left. I went home.

Her mother and her aunt encouraged her to stop thinking about the baby; her mother made her delete the photograph from her cell phone. On the other hand, her boyfriend chose to see the baby after she had died, and continued to speak about her. They went to MH



together months after the death to try to find out what had gone wrong. However, there seemed to be a part of Zodwa that didn't want to make sense of what happened:

You must want to - want the help and want to get out of it. I don't think I want to get over it and want the help. I don't want it. I don't know why.

I just want to speak about it for people to know that I went through something like this and that's it, I think. Not speak about her in a way that I need someone to help me to get over her or something. It's just to let a person know that Zodwa had a child in 200-, and the child died according to things she doesn't know.

Although it was 26 months ( $M = 22$ ) since her baby's death, and she had had a subsequent baby, Zodwa showed far less evidence of having made sense of the loss than any other mother apart from Vuyokhazi. Her earlier difficulties in talking about emotions were still evident. The unresolved grief may have been in part due to the fact that she had another baby so soon after the death (Badenhorst & Hughes, 2007; Robinson et al., 1999; Turton et al., 2009), but her ruminative style appeared to compound her difficulty (Baddeley & Singer, 2009; Nolen-Hoeksema et al., 2006). In addition, she did not know the medical reason for the baby's death and she had no recourse to religious explanation as she does not believe in "that reasoning, spiritual thing." When asked if she had come to understand why it had happened, she said, "There's no such thing." Despite the length of time since the death, her attachment to her baby was clearly still very strong. The presence of a strong, continuing bond such as this coupled with the absence of any larger meaning has been correlated with higher Complicated Grief (or PGD) symptomatology (Neimeyer et al., 2006).

The interview with Zodwa leaves many questions about her and her context unanswered. What underlies her evaluation of her home as a "dangerous place"? Why was she unable or unwilling to engage with her sister's death? Why, despite her close circle of support, does she emerge as a lone figure? It may be that she falls into the group of people for whom traumatic loss easily assimilates into pre-existing *negative* meaning structure, and reinforces negative coping patterns. In these instances, the bereaved often have disorganised attachment styles or have been subjected to ongoing trauma and stressors (Currier et al., 2009).

Research suggests that unsuccessful attempts to make meaning after a traumatic loss are associated with the worst outcomes (Keese et al., 2008; Neimeyer et al., 2010), and Zodwa displays some of the symptoms of Prolonged Grief Disorder (PGD) (such as intrusive thoughts about and yearning for the deceased; a sense of numbness, detachment, or absence of emotional responsiveness; feeling life is empty; feeling that part of oneself has died). The directionality of this is not clear, however, because PGD can disrupt meaning-making

capacities (Lichtental et al. 2010). Did Zodwa struggle to make meaning because of symptoms associated with PGD, or did these symptoms develop because she had not found meaning? Was her reduced sense of agency because she had not been able to make meaning of the loss, or had she been unable to make meaning because she had diminished agency?

The nature of cross-sectional research means that these remain unanswered, but they do suggest that simplistic models of meaning-making cannot account for individual patterns of grieving.

### **Meaning-Making when Socio-Economic Circumstances Limit Options**

How does being poor affect meaning-making following perinatal loss? This study does not reveal any clear answers. The women in this study seemed to engage with meaning-making in similar ways to those described in other research. Their meanings are strongly influenced by motherhood discourses and religious explanations, but these are not unique to their socio-economic situation. It is possible that their inferior medical care means that they tended to focus on blaming medical staff more than would happen in other settings.

Personal agency and social support seem to be more important predictors of successful meaning-making than contextual factors. Underlying this is the women's need to have some sense of control over their lives, and a sense of narrative continuity or coherence. These are the very things that trauma ruptures (Neimeyer et al., 2010). It is possible that where even a small vestige of these two elements remains, the mothers have a foundation on which to reconstruct meaning. It is likely that personal agency and social support are so important because they provide these starting blocks for meaning-making. A sense of agency provides women with continuity in identity, as well as a belief that they can effect change. Social support can provide similar continuity in terms of social identity and stability. In addition, people close to the bereaved mother are able to provide a kind of collective agency which can help to change difficult situations and reframe interpretations.

The data suggest that women who have both a strong sense of personal agency and strong social support are in the best position to reconstruct meaning, as they are able to use their support in ways that are most helpful to them without having their own desires and goals subsumed by dominant collective interests. However, women who have either well-developed personal agency or strong social support are also able to make meaning of their loss. What their meanings are depends to an extent on whether they are more invested in social relationships or in personal goals. The critical factor is whether the meanings achieved give them a measure of understanding, emotional comfort and hope for the future.

Finding hope may be a particularly challenging task within the context of poverty. For woman like Vuyokhazi, Nontombi and Zodwa, whose helplessness and fragmentation in the face of their loss prolongs their distress, meaning-making is a difficult, and perhaps unachievable, task. In the absence of social support and personal agency, therapeutic intervention may be required to facilitate the process.

## Chapter Five: Conclusion

In this chapter, the main findings of the study are summarised. The limitations and the significance of the study are discussed, and implications for clinical practice and further research are suggested.

### Summary of Main Findings

This study explored the narratives of 15 women who told the stories of losing their babies and how they tried to come to terms with the loss. The aim was to examine how they made meaning of what had happened.

In order to understand the context in which the mothers experienced perinatal loss, the way they described their environments was explored. A picture emerged of medical care which they perceived as inadequate (sometimes negligent), difficulty in finding a regular source of income, disrupted education (either due to the pregnancy and death, or financial constraints), living in uncomfortable or conflicted situations, and struggling to find money for the funeral, better medical care, and even transport.

Even though they were accustomed to hardship, the mothers still seemed to experience their loss as traumatic, and engaged in meaning-making in similar ways to bereaved mothers from more affluent backgrounds, as described in other studies (Davis et al. 1998; Wheeler, 2001).

Firstly, they attempted to integrate the loss into their identity and goals. This involved coming to terms with what it meant to be a mother who has no child. Some of the women continued in this role either through mothering their own children, trying to have another baby, or looking after other people's children. Two of them put aside their mothering role and hoped to pursue their personal goals which did not involve being in a relationship or having a child.

Secondly, there was a great deal of evidence that the mothers needed to affirm the depth of their loss by acknowledging that the baby was a real person to be mourned. This was done through mementoes, conversations with others, thinking about the baby, and engaging in social rituals. These also served to establish a continuing bond with the baby.

Thirdly, all the women tried to make sense of their loss by searching for concrete and existential reasons for why the baby had died. It was difficult for many of them to grasp and accept the medical reason for the death. A number of them (eight) blamed the medical staff for what had happened. Some blamed other people for damaging the pregnancy either by supernatural means, or because of conflict. Blaming medical care or other people was reinforced in conversations with people within their social support systems. Many of the

women blamed themselves, which either increased their distress or enabled them actively to make different decisions with the next pregnancy. Religious meanings helped some of the women to accept their loss, as they understood the death to be part of God's will. Even when other explanations have been found, these underlying spiritual reasons seemed to be as, if not more, important in comforting the mothers.

There did not seem to be any obvious common links between the women's life circumstances and how they made sense of the loss. Strong cultural norms played a crucial role in reinforcing the importance of motherhood and the enormity of losing a child. Fourteen of the 15 women were part of religious communities which informed their understanding of the loss. However, these social understandings were not necessarily directly related to socio-economic factors and could equally apply to people in more affluent circumstances. The way the mothers made sense of their loss was not affected as much by their particular contexts as by how they positioned themselves within that context.

Close analysis of the data indicated a pattern of four different kinds of narratives, depending on the extent to which the women portrayed themselves as agentic or surrounded by social support. In the first kind of narrative, women had little sense of agency and little social support. These narratives did not show much evidence of meaning-making, and the women displayed considerable distress. In the second kind, women had a strong sense of agency and almost no social support. In these narratives, meaning revolved around revising and achieving personal goals. In the third kind of narrative, the women had strong social support and somewhat diminished agency. Their meanings were largely determined by social or religious norms, and their personal goals were of less importance. In the fourth kind of narrative, the women had a strong sense of agency and strong social support. They drew on social meanings which were helpful to them in achieving their personal goals. The women with more social support tended to be more financially secure, but financial security alone did not predict that meaning would be successfully negotiated.

Zodwa did not fit into any of the above narrative patterns, as she could not find meaning despite her strong social support. Her inability to do so might be related to her temperament, in particular her ruminative style, or a history of difficulties which it was beyond the scope of this study to examine.

How do the challenges and limitations of socio-economic difficulties affect meaning-making following perinatal loss? What seems to be more important than contextual factors is the presence of effective meaning-making mechanisms which are linked to personal agency and social support. Women who portray themselves as agentic are likely to have a strong

sense of continuity in personal identity, and the reflective capacity to think about their loss and make decisions to change their lives. Those who have strong social support will be aided in the meaning-making process by conversations, social validation of their loss, and financial or practical help which may protect them against some of the feelings of helplessness which being poor can engender.

### **Limitations of this study**

Because this was a cross-sectional study, it was not possible to investigate how meaning-making evolved over time. At best, it presents an understanding of meaning-making as reflected in a single unique narrative specific to the time and context of the interview. This study was not intended to produce results that could be generalised, as the sample size was small. Findings cannot be considered conclusive, but can be used as the basis for further study.

### **Significance of this Study**

As a small window into the lives of mothers who are part of a hard-to-reach population, this study gives a glimpse into a painful reality not often recognised. Despite the fact that the women were interviewed in their second language, they created moving and evocative narratives, often expressed in beautifully poetic idiom. It is hoped that the portrayal of these narrative accounts will generate a deeper understanding of the “disenfranchised” grief of perinatal loss.

Practically, health care workers and mental health professionals who work with perinatally bereaved mothers could be more aware of specific issues which may be clinically significant in grief outcomes.

Firstly, they should be aware of the prolonged, complex and individual nature of the grieving process. In particular, it should not be assumed that because the women are accustomed to difficulties, or because the pregnancy is unplanned, that the death will be any less traumatic.

Secondly, given the importance of personal agency in meaning-making, efforts should be made to instil a greater sense of control in the women wherever possible. This includes informing her as clearly as possible about baby’s medical condition, giving her choices where this is appropriate (e.g. if she wants to be on her own or to share a room; choosing whom she wants to contact), validating her feelings, and delaying discussing issues of blame (e.g. if she booked late). While this last issue needs to be dealt with sensitively, it should not be avoided, as taking responsibility for her part in the baby’s death could be ultimately empowering for the mother.

Thirdly, given the importance of social support, close family members should be allowed to visit, to see the baby, and where possible, to hold the baby. In the absence of family members, close friends could play a similar role.

Fourthly, because knowing the cause of the baby's death seems to be so central to most women's meaning-making, medical staff should consider ways in which this can be communicated as clearly as possible to the mother, and possibly to those in her support system who can help her to understand what has happened.

Fifthly, counselling interventions may be strengthened by adopting strategies which increase mothers' sense of self-efficacy, as this may be important in helping them to engage successfully in meaning reconstruction.

### **Further Areas of Research**

This study raises the issues of how personal agency and social support facilitate meaning-making following bereavement, an area which has not hitherto been researched. A fuller investigation (preferably using mixed methods) could explore whether these are consistently associated with successful meaning reconstruction; whether absence of either or both predicts difficulty in meaning-making; and what this means for intervention strategies.

A great deal more research into poverty and grief is still required, particularly with clearer focus on specific aspects of poverty such as social instability, inadequate medical attention, and dealing with multiple losses.

### **Meaning-Making: An Act of Resilience**

Earlier on, de Kok et al. (2010) were quoted as saying "being a woman, and being poor, increases the risk of experiencing loss, aggravates its consequences, and limits one's options to prevent, manage, and cope with loss" (p.10). For the most part, the women in this study demonstrated how, within their difficult circumstances, they tried to make meaning of their babies' deaths as a way of instilling hope and purpose into their lives. Ayanda's concluding words capture the sense of perseverance and resilience evident in many of the narratives:

But now I think I'm fine, I can say, but not quite fine; not quite right.  
I think I'm going to be fine. I am going to be fine, because I'm getting there.  
I'm getting there.

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## **Appendix A (i): Informed Consent Form - English**

Dear Participant

I am doing research on how mothers whose babies have died before or just after birth deal with their loss. I am interested in interviewing people whose loss happened at least one year ago, and I would value your participation in the study. I hope that what I find out will help other women who experience this kind of loss and improve the quality of care they receive from the professionals who work with them (such as doctors, nurses, church workers, and counsellors).

The study will involve doing one-on-one interviews. The interview will last for about an hour, although it may take longer. The conversation will be recorded, and then transcribed (written). If you decide to participate, I will ask you some questions about yourself and your loss. I would like to hear how you have coped with your baby's death, and what made it easier or more difficult. The interview will be held either at your home or in another place where you feel comfortable.

There are no serious risks involved in the study, although it might be upsetting for you to talk about your loss.

There are no direct benefits to you from this study, but the knowledge gained will help other mothers who experience loss. Although the purpose of the interview is not to provide counselling, talking about your loss may help you in dealing with your grief.

If you decide to participate, I will keep your identity confidential, and will use a pseudonym (false name) in writing up the report. I will use your baby's name only if you give me permission to do so. The recordings and written copies will be kept in my office at home. Only my supervisor and I will be allowed to read them.

You will not be paid anything for participating, but your transport costs to and from the interview will be paid.

If you find that talking about your loss upsets you, and you would like to speak with a counsellor, you can either meet with me again, or one of the social workers at Mowbray Maternity Hospital.

You do not have to take part in this study. If at any stage you would like to stop, you have a right to do so. If, after the interview, you decide that you do not want your story to be used, you may ask me to leave it out of the study.

If you have any further questions or concerns please contact me (Colleen Sturrock).

Telephone: 083 321 7299

Email: strcol004@uct.ac.za

### Signatures

\_\_\_\_\_ has been informed of the nature and the purpose of the research described above including any risks involved. She has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the research participant.

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

I have been informed about this research study and understand its purpose, possible benefits, risks and discomforts. I agree to take part in this research. I know that I am free to withdraw this consent and quit this project at any time, and that I will not be penalised for withdrawing.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_ has been informed that the interview will be recorded and transcribed.

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

I give consent for the interview to be recorded and transcribed.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date



## Appendix A (ii): Informed Consent Form - Xhosa

Dear Participant

I am doing research on how mothers whose babies have died before or just after birth deal with their loss. I am interested in interviewing people whose loss happened at least one year ago and I would value your participation in the study. I hope that what I find out will help other women who experience this kind of loss and improve the quality of care they receive from the professionals who work with them (such as doctors, nurses, church workers, and counsellors).

**Ndenza uphando ngomama ababhujelwe zintsana xa zigqitywa kuzalwa okanye ezibhubhe nje phambi kokuba zizalwe. Ndinomdla wokudlana indlebe nabantu abehlelwe yilelahleko kunyaka ogqithileyo, ndakuyibulela kakhulu inxaxheba yakho koluphando. Ndiyathemba ukuba oko ndikufumanisileyo kuyakunceda abanye oomama abahlelwa yilahleko enjena, kwaye iphucule noncedo abalufumana kwabasemagunyeni (njengoogqirha, abongikazi, abasebenzi basecaweni kunye namakhansela)**

The study will involve doing one-on-one interviews. The interview will last for about an hour, although it may take longer. The conversation will be recorded, and then transcribed (written). If you decide to participate, I will ask you some questions about yourself and your loss. I would like to hear how you have coped with your baby's death, and what made it easier or more difficult. The interview will be held either at your home or in another place where you feel comfortable.

**Oluphando luzakubandakanya udliwano-ndlebe nawe oluzakuthatha iyure, mhlawumbi nangaphezulu. Incoko leyo iyakurekhodwa, ibe sele ibhalwa. Ukuba ugqiba ekubeni uthathe inxaxheba, ndizakukubuza imibuzo ngawe kunye nokulahlekelwa kwakho lusana. Ndingathanda ukuva ukuba umelana njani na nobomi emva kokuswelekelwa lusana lwakho, nokuba yintoni na eyakuncedayo okanye yakubaxa ukukhathazeka kwakho. Oludliwano-ndlebe luzakubanjelwa ekhayeni lakho okanye kwenye indawo ongathi uzive ukhululeke kuyo**

There are no serious risks involved in the study, although it might be upsetting for you to talk about your loss.

**Akukho bungozi bunxulumene noluphando, nangona ke unokuphazamiseka emphemfulweni xa uthetha ngongasekhoyo**

There are no direct benefits to you from this study, but the knowledge gained will help other mothers who experience loss. Although the purpose of the interview is not to provide counselling, talking about your loss may help you in dealing with your grief.

**Akukho nzuzo eza kuwe ngoluphando, kodwa ulwazi esilufumeneyo luzakunceda oomama abathe balahlekelwa. Nangona injongo yoluphando ingekokukukhansela, ukuthetha ngelahleko yakho kungakunceda ekuhlangabezaneni nelahleko yakho.**

If you decide to participate, I will keep your identity confidential, and will use a pseudonym (false name) in writing up the report. I will use your baby's name only if you give me permission to do so. The recordings and written copies will be kept in my office at home. Only my supervisor and I will be allowed to read them.

**Ukuba ugqiba ekubeni uthathe inxaxheba, ndiyakuligcina liyimfihlo igama lakho, kwaye ndisebenzise igama elingelilo xa ndibhala ingxelo. Ndakulisebenzisa igama lomntanakho kuphela xa undinikile imvume. Esikurekhodileyo, nesikubhalileyo sizakukugcina eofisini yam ekhaya. Ngumphathi wam kuphela ozakubanemvume yokukufunda**

You will not be paid anything for participating, but your transport costs to and from the interview will be paid.

**Awuzukubhatalwa ngokuthatha inxaxheba, kodwa imali yokukhwela uze koludliwano-ndlebe futhi uphinde ekhaya uzakuyihlawulwa**

If you find that talking about your loss upsets you, and you would like to speak with a counsellor, you can either meet with me again, or one of the social workers at Mowbray Maternity Hospital.

**Ukuba ufumanisa ukuthetha ngokuswelekelwa kwakho kukukhathaza kakhulu, kwaye ungathanda ukuthetha nekhansela, ungaphinda udibane nam, okanye nomnye wonontlalontle baseMowbray Maternity Hospital**

You do not have to take part in this study. If at any stage you would like to stop, you have a right to do so. If, after the interview, you decide that you do not want your story to be used, you may ask me to leave it out of the study.

**Awunyanzelekanga ukuba uthathe inxaxheba koluphando. Nanini na usiva ngathi kufuneka umise, unalo ilungelo lokwenza oko. Ukuba ngaba emva koludliwano-ndlebe ugqiba ekubeni awufuni ibali lakho lisetyenziswe, ungandicela ukuba ndikushiye ngaphandle koluphando.**

If you have any further questions or concerns please contact me (Colleen Sturrock).

**Ukuba nga uneminye imibuzo okanye ixhala ngoku nceda uqhakamshelane nam uColleen Sturrock.**

Telephone: 083 321 7299

Email: strcol004@uct.ac.za

**Signatures**

\_\_\_\_\_ has been informed of the nature and the purpose of the research described above including any risks involved. She has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the research participant.

Wazisiwe ngohlobo, nenjongo yoluphando luchazwe apha ngentla, kunye nabuphi ubungozi obunokubakhona. Ulinikiwe ixesha lokubuza nayiphi na imibuzo kwaye nalembuzo iphendulwe kangoko umphandi enokwenza. Ikopi esayiniweyo yaleform yemvume inganikwa umthathi-nxaxheba koluphando.

\_\_\_\_\_  
Researcher

Date

\_\_\_\_\_  
Umphandi

\_\_\_\_\_  
Umhla

I have been informed about this research study and understand its purpose, possible benefits, risks and discomforts. I agree to take part in this research. I know that I am free to withdraw this consent and quit this project at any time, and that I will not be penalised for withdrawing.

Ndazisiwe ngoluphando kwaye ndiyayiqonda injongo yalo, naloko kungafumaneka ngalo, kunye nobungozi, nokuphatheka kakubi okunobakhona. Ndiyavuma ukuthatha inxaxheba koluphando. Ndiyayazi ukuba ndikhululekile ukuyirhoxisa lemvume ndimke koluphando nanini na, nokuba futhi andiyikubizwa nto ngokurhoxa

\_\_\_\_\_  
Participant

Date

\_\_\_\_\_  
Umthathi-nxaxheba

\_\_\_\_\_  
Umhla

\_\_\_\_\_ has been informed that the interview will be recorded and transcribed.

Wazisiwe ukuba oludliwandlebe luzakurekhodwa futhi lubhalwe phantsi.

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

Umphandi

Umhla

I give consent for the interview to be recorded and transcribed.

Ndinika imvume yokuba oludliwano-ndlebe lurekhodwe futhi lubhalwe phantsi

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

Umthathi-nxaxheba

Umhla

## **Appendix B: Interview Guidelines**

### **1. What did the pregnancy mean for the mother and how did circumstances affect this meaning?**

1. Can you tell me about your pregnancy?
2. How did you feel about being pregnant?
3. How did your pregnancy progress? How were you physically?
4. Did you go for regular checkups? What was it like for you going to the clinic?
5. Were there any concerns about your health or the baby's health?
6. How far into the pregnancy did you work? How was that for you?
7. What else was going on in your life during the pregnancy?

### **2(a) The mother's experience of the birth and death of her baby (stillbirth).**

1. Can you tell me about your labour and your baby's birth?
2. How did you find out about your baby's death? (Did you know before delivery that your baby was dead? How did the medical staff speak to you/ explain it to you?)
3. What happened when you found out about your baby's death? Do you remember how you felt and what you did?
4. What were you told about the reasons for the baby's death? Do you think that you were told enough or would you like to have known more?
5. Were you able to hold your baby? How was that for you?
6. Did you keep any mementoes of the baby? Has that helped /been difficult for you in any way? Could you explain?
7. What help did you get from medical staff or family or friends at the time?

### **2(b) The mother's experience of the birth and death of her baby (neonate).**

1. Can you tell me about your labour and your baby's birth?
2. What happened when you heard that your baby was sick? How did the medical staff explain the situation to you?
3. Can you tell me about the hours/days when your baby was still alive? Do you remember how you felt and what you did?
4. What were you told about the reasons for the baby's death? Do you think that you were told enough or would you like to have known more?
5. Were you able to hold your baby? How was that for you?

6. Did you keep any mementoes of the baby? Has that helped /been difficult for you in any way? Could you explain?
7. What help did you get from medical staff or family or friends during that time?

### **3. Mourning**

1. What usually happens in your community when a baby dies?
2. I asked you earlier about a burial for you baby. Can you tell me a bit more about that?
3. If you remember, could you tell me what happened in the first few days or weeks after your baby's death?
4. What helped you during this time?
5. What was difficult for you during this time?

### **4. The effect of the loss**

1. Were things different for you in your life after the death of your baby? Can you explain?
2. Do you still think about your baby? How do you feel about him/her and your loss now? Does it still affect you? How?

### **5. The meaning of the loss**

1. When you think about your baby, do you sometimes ask yourself why it happened? What reasons have you thought of?
2. Do you ever wonder about what could have saved your baby? Could you tell me about your thoughts?
3. Is there anything particular that has helped you understand or deal with your loss? Could you tell me more about that?
4. Has anything made it more difficult to understand and deal with your loss? In what way?

### **6. Reflection questions**

1. If you had had more money, how would you have done things differently?
2. Since you have been through this loss, what would you say to another woman who has lost a baby?
3. How do you feel now after talking about your baby?

### Appendix C: Demographic Details and Fertility History of Participants

	Age	Education	Relationship Status	Employment	Number of pregnancies	Pregnancy intention	Months since death	Gestational age in weeks or months	Previous children	Subsequent children
Anne	20	Gr 12	Single	Unemployed; supported by mother	1	unplanned	25	42		
Ayabonga	19	Gr 12	Single	unemployed	1	unplanned	17	40		
Ayanda	29	Gr 12	Lives with boyfriend	Unemployed; supported by boyfriend	1	unplanned	25	7 mnths/ 7mnths		6 months pregnant at interview
Bongeka	29	At College	Single	studying	1	unplanned	19	5mnths		
Jean	28	Gr 10	Married	Unemployed; supported by husband	2	planned	17	24	Girl (8)	Boy (3mnths)
Naziema	24	Gr 12	Married	Unemployed; supported by husband	4	planned	30	28	Two girls (?), Boy (?)	
Nonkhululeko	34	Gr 10	Single	unemployed	3	unplanned	12	28	Girl (15), boy (11)	
Nontombi	28	Gr 12	Still with boyfriend	Domestic worker	2	unplanned	24	40	Boy (4)	
Norma	35	Gr 8	Married	Factory worker	2	planned	17	40	Girl (10)	
Nosandla	27	Gr 12	Married	Cashier	2	planned	12	6mnths	Girl (4)	
Nosipho	21	Gr 11	Still with boyfriend	Unemployed; supported by grandmother	2	unplanned	25	6mnths	Boy (4)	Boy (5 mnths)
Ntombekhaya	22	College diploma	Has new boyfriend	Unemployed; supported by grandmother	1	unplanned	24	8mnths		
Vuyokhazi	20	Gr 12	Single	unemployed	1	unplanned	15	6mnths		
Zanele	28	College diploma	Has new boyfriend	Junior financial analyst	1	unplanned	25	6mnths		Boys (14mnths; 6 weeks)
Zodwa	23	Gr 12	Still with boyfriend	Security guard	1	unplanned	26	7mnths		Boy (2)
<b>Mean</b>	25,8						22,8			

### Appendix D: Synopsis of Narratives

<b>Anne (Zack)</b>	I did not want the baby because I was young and at college. I couldn't have an abortion, so I took drugs. It is my fault that my baby died. I felt very guilty, but now I am dealing with it and my life will get better. I need support from those close to me, but I also need to make my own decisions and lead my own life. I am a totally different person since my baby died.
<b>Ayabonga (Qama)</b>	I have a very hard life. I didn't want a baby because I have no one to support me, but my boyfriend wouldn't let me have an abortion. Then he left me. I accepted the pregnancy and needed the baby because I have no one else. I was very sad that she died, but I am a strong woman and I will make a better life for myself. But I still need some help.
<b>Ayanda</b>	I had the first miscarriage in 2007, even though I had been regularly to the clinic. I was very depressed and drank afterwards. My boyfriend and I split but got together again. I didn't book for the next pregnancy because I didn't want to get my hopes up. I was told the second baby wouldn't survive but she cried when she was born and died on my chest. I worry a lot about this. What is wrong with me? I am pregnant again and worry that I will lose this baby too.
<b>Bongeka (Onakho)</b>	I wasn't ready to fall pregnant, but I was happy when I did. I was in an abusive relationship and my boyfriend beat me even during the pregnancy. My baby died because of my boyfriend and because I had to work hard while I was pregnant. I have left my boyfriend and am at college now and just want to look to the future.
<b>Jan (Corbin)</b>	Family is important to me. I really wanted another child. I do not know why he died: stress due to conflict with mother-in-law, vitamins, smoking, neglect to give him oxygen? His death was terrible, but my family supports me and I am doing ok. Having another baby has healed me. His death has made me a better person and a better wife.



<b>Naziema (Mohammed Yaseem)</b>	I very much wanted to be pregnant, but it was a difficult and complicated pregnancy. I thought my baby was going to make it, but his time had come. He was part of us for a short while, but he is in a better place now. I can sometimes feel he is still here with me. I keep myself busy and try to be strong for my other children
<b>Nonkululeko (twins)</b>	I didn't want another child now, but I accepted the pregnancy. I lost my babies, and then was sick so I lost my job. My boyfriend has left me. Everything has gone wrong. My daughter has to leave school because I can't support her. I will be ok if I could get a job.
<b>Nontombi (Bayilitha)</b>	My baby girl died because the nurses at the MOU didn't help me when I was in labour and didn't help me when my baby was crying so much until it was too late. No one really understands my pain, but I try to keep busy and be strong for my other child.
<b>Norma (Noah)</b>	We really wanted this baby, but he would have suffered if he had lived. God knows what is best. I have a very supportive family and we are at peace.
<b>Nosandla</b>	My husband and I were very excited about having another baby. Even though I could feel my baby coming out, the nurses at the MOU wouldn't let me deliver there, because I was booked at MH. I waited for a long time for the ambulance. I heard my baby cry, but he didn't live for long. God gives and God takes away, but I still blame the people at the MOU. That child should have survived. We are planning another baby.
<b>Ntombekhaya (Lisa)</b>	I have had a very supportive upbringing and although I made a mistake in falling pregnant and in not looking after the pregnancy, I can learn from my mistakes and move forward. I felt terrible at losing my baby, but I really want another child and I am able to support it because I am strong and able to earn and save money.
<b>Nosipho</b>	I did not want another baby, and I did not book into the clinic. My baby died because of this. I was very sad and angry with myself, but I have had a lot of support. I looked after my next baby well and although I will never forget my baby, things are going better.

<b>Vuyokhazi</b>	I have broken up with my boyfriend and I am all alone. The pregnancy was unplanned. It was my boyfriend's fault that the baby died. Maybe if she hadn't died, I would still be with him. There are no answers for me.
<b>Zanele (Lihle)</b>	I didn't plan to have a child, but accepted the pregnancy and went to the clinic regularly and followed traditional protocols. My baby was premature and small, but I wonder if the doctors couldn't have done more to save her. I was very upset – even tried suicide- but I dealt with my grief with the support of my amazing new boyfriend and friends. I found out from a private doctor what had gone wrong and have since had two boys who have filled the gap left by Lihle's death.
<b>Zodwa (Sibongile)</b>	I thought I would never be able to have children, so the pregnancy was a surprise. I think my child died because MH didn't handle the situation properly. I don't know why she died. I don't want to get over it because I didn't know her and I don't want to forget her. Something is still missing. I worry constantly about my next child, Mehluli.

### Appendix E: Transcription Key

Symbol/punctuation	Explanation
...	Indicates a word or words omitted
(3)	Indicates a pause, with the number denoting the length of the pause in seconds
...	Indicates where words trail off into silence
<i>My family feel strongly ...</i>	Italicised words indicate text in Afrikaans
He ( <i>her boyfriend</i> ) was always there.	Italicised bracketed words within quote provide necessary explanations.
-	Indicates disjointed sentences, where phrases are not completed before a new idea is introduced without any pause.